Dissociating the Disease from the Diseased

by

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ABSTRACT

Lung Cancer Alliance, a nonprofit organization, released the "No One Deserves to Die" advertising campaign in June 2012. The campaign visuals presented a clean, simple message to the public: the stigma associated with lung cancer drives marginalization of lung cancer patients. Lung Cancer Alliance (LCA) asserts that negative public attitude toward lung cancer stems from unacknowledged moral judgments that generate 'stigma.' The campaign materials are meant to expose and challenge these common public category-making processes that occur when subconsciously evaluating lung cancer patients. These processes involve comparison, perception of difference, and exclusion. The campaign implies that society sees suffering of lung cancer patients as indicative of moral failure, thus, not warranting assistance from society, which leads to marginalization of the diseased. Attributing to society a morally laden view of the disease, the campaign extends this view to its logical end and makes it explicit: lung cancer patients no longer deserve to live because they themselves caused the disease (by smoking). This judgment and resulting marginalization is, according to LCA, evident in the ways lung cancer patients are marginalized relative to other diseases via minimal research funding, high-mortality rates and low awareness of the disease. Therefore, society commits an injustice against those with lung cancer. This research analyzes the relationship between disease, identity-making, and responsibilities within society as represented by this stigma framework. LCA asserts that society understands lung cancer in terms of stigma, and advocates that society's understanding of lung cancer should be shifted from a stigma framework toward a medical framework. Analysis of identity-making and responsibility encoded in both frameworks contributes to evaluation of the
significance of reframing this disease. One aim of this thesis is to explore the relationship between these frameworks in medical sociology. The results show a complex interaction that suggest trading one frame for another will not destigmatize the lung cancer patient. Those interactions cause tangible harms, such as high mortality rates, and there are important implications for other communities that experience a stigmatized disease.
DEDICATION

For my mom
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CHAPTER 1

INTRODUCTION

Lung Cancer Alliance’s “No One Deserves to Die” campaign made the audience uncomfortable. It made the audience think about its attitude toward lung cancer patients. And now, Lung Cancer Alliance has moved on to another type of campaign. However, the attention grabbing “No One Deserves to Die” campaign of June 2012 deserves an in depth examination. The campaign aimed to dissociate stigma from lung cancer, but is exemplary of larger epistemological issues of understanding disease.

This thesis offers a case study of a recent example of framing the perception and experience of disease in terms of stigma. The case study examines Lung Cancer Alliance (LCA), a nonprofit organization, and its “No One Deserves to Die” campaign. This campaign asserts that lung cancer is stigmatized in American culture, and calls on society to reform its attitude about this disease. Neither the campaign, educational materials, nor the staff at Lung Cancer Alliance demonstrate a unified theory of stigma. Furthermore, the organization does not present concrete, primary evidence for stigma in society. This is significant to the analysis of a campaign for a nonprofit organization whose mission is to “end injustice” to lung cancer patients caused by stigma. The organization draws an implicit parallel with other cancers, highlighting the apparent disparity of research funding and attention between lung cancer and breast cancer. Effectively, the parallel looks to a disease (breast cancer) that has experienced what Lung Cancer Alliance considers success. By comparison, lung cancer is still blamed on the patient, whereas

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1 The images included in the campaign can be found in Appendices A and B.
breast cancer is no longer understood in those moral terms and is now understood epidemiologically. Susan Sontag, a breast cancer patient herself, stated “[the language about cancer] must change, decisively, when the disease is finally understood and the rate of cure becomes much higher.” By this, Sontag means the moral implications that accompany cancer will diminish as the disease becomes less of a public health issue. If this were the definition of destigmatization, breast cancer could be considered destigmatized as a result of the emergence of multiple drugs were found to effectively treat breast cancer. This comparison is highly relevant to lung cancer, currently the second highest cause of death in the United States. Lung Cancer Alliance is looking for destigmatization of lung cancer via treatments and awareness. However implicit, this is the picture of destigmatization for which LCA is striving.

Further, this analysis is extremely relevant to the Lung Cancer Alliance case as the organization not only pushes for medical treatment but also social understanding and tolerance of those affected by the disease. LCA asserts that the public carries a certain set of ideas, assumptions, and practices that structure or frame its understanding of disease, in this case, lung cancer specifically. The organization characterizes social understanding of lung cancer by attaching “stigma” to the common set of assumptions about lung cancer, which they judge to be the incorrect method of understanding. This “incorrect method” for understanding disease is a barrier preventing lung cancer from achieving any appreciable progress in either raising federal funding or decreasing mortality rate. LCA reveals this assessment of the stigma framework, or structure for understanding, in a

minimalistic way in the campaign and other LCA materials. However, its presence is powerful. The resulting stigma narrative of lung cancer colors the connection between lung cancer and stigma in negative language. The “No One Deserves to Die” television advertisement tells the audience “Lung cancer doesn’t discriminate; neither should you.” This account of the story tries to offer a reason for shifting the frame through which relationships between the disease, the individual’s identity and responsibility are made. However, it glosses over how and where these relationships are made. LCA’s call for reordering public understanding of disease, by changing its set of common assumptions and practices, both reveals LCA’s perspective of how society currently understands lung cancer, and implies that LCA has a picture of what lung cancer would mean if it were destigmatized. When LCA observes a change in their proxy measures for stigma, more funding and lower mortality rate for example, it would signify to the organization that a shift away from the stigma frame has occurred to some extent.

This case suggests that the stigma frame has come to circulate in general discourse. As such, it has taken on a distinct meaning that is so clear that Lung Cancer Alliance need not explain what stigma means. The organization does not provide a definition of stigma and has a proxy measure for stigma experienced in society. Stigma as a concept is not easily quantified. However, the campaign has traction without direct evidence of stigma. The minimalist nature of the campaign reflects the common sense arguments the organization makes about stigma and its function in framing public understanding of lung cancer. A negative perspective of the disease in question has become embedded in the definition of stigma, shown by a limited genealogy of the concept. LCA takes this attitude as a given. LCA assumes the audience understands stigma as exclusionary and
negative. Little theorizing regarding the definition or support for their claims occurs in either the campaign itself or the educational materials. It is significant that LCA provides evidence that is actually a secondary measurement, a proxy, of stigma because it tells a simple story. In utilizing these proxy measures, and by not utilizing a complicated direct measurement of stigma, LCA does not have to convince the audience that what is being presented is stigma. LCA is able to use statistics to paint a simple story that the harms captured in lung cancer’s low survival rate and funding are caused by stigma. The simplicity of the story predisposes the audience to accept the narrative LCA provides rather than uncover its underlying complexity. LCA’s simplification of the reasoning can be mapped as such: lung cancer stigma = unjust attitude = exclusion. The narrative of this understanding ignores how these connections are made.

I will demonstrate that this simple map represents a significant amount of work that LCA does not address. I am interested in interrogating the complex pieces of the narrative that are flattened, or oversimplified, by explaining this social problem in terms of stigma. In trying to understand what function stigma plays, it is useful to ask: how is stigma operationalized in the Lung Cancer Alliance advertising campaign? By operationalized, I mean how has LCA put the background theoretical work to use in order to achieve the goal of confronting public attitudes about lung cancer in the campaign? Put differently, what work is the concept of stigma doing for LCA in its campaign? What features of the concept are packed into the term of stigma that allow it to be used in this way? I will demonstrate that using the stigma framework flattens out this relationship. How does their use of the stigma narrative in this way make this possible?

From my analysis of the case, informed by Charles Rosenberg’s work explaining
disease frames, it becomes clear that relationships of disease, identity-making and responsibility are encoded with normative claims and disease frames are morally laden. Lung Cancer Alliance (LCA) says stigmatization is a moral framing of disease. Other scholars have identified disease frames as an interesting area for discussion, as framing disease is an important place to observe social relationships. Charles Rosenberg states that disease is an important locus through which social relationships are negotiated by asserting that “every aspect of an individual’s social identity is constructed—and thus also is disease,” and “once crystalized… disease serves as a social actor and mediator.” By this, Rosenberg is proposing an idea that interacts nicely with Ian Hacking’s proposal of “dynamic nominalism” in order to say that disease functions as a tool to categorize people in new ways and, conversely, as an existing category in which to place types of people as they emerge into public consciousness. For the purposes of this thesis, the concept of a disease frame will be considered as a given due to an extensive amount of research and discourse that has already negotiated the definition of a disease frame. If we set aside any disagreements about what a disease frame is, and, in this thesis, consider a disease frame to be a set of assumptions informing understanding and a method of practices that constitute the representation of some disease. Rosenberg’s discussion of disease frame indicates a frame is a system of understanding and responding to a disease

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5 Ibid., 10
in such a way that incorporates place, time-period, and social considerations, in addition to the biological nature of the disease. If we use Rosenberg’s formulation of ‘disease frame,’ it is clear that it is important background for the case study and questions at hand.

This specific case and disease frame, is interesting because it is applied to a disease, lung cancer, that society continues to blame on the individual. As such, society inserts normative claims about the identity of the individual with lung cancer. This moral frame, or method of understanding, is not appropriate, according to LCA, because it allows for injustice toward lung cancer patients. In constructing the problem of injustice in this particular way, Lung Cancer Alliance collapses a complex problem of social attitudes, and the unmediated effects of those attitudes, into a simple statement that says society-at-large has the wrong attitude about stigma and society is at fault for the resulting injustice. The simplicity of the statement masks the true meaning of its implicit components. By packaging the problem as stigma, LCA is able to move forward with simple statements without theorizing the problem. The goal here is not to speculate whether they should or should not undertake this project in this way, but to think about how they tackled the topic and why their method is significant.

LCA did not have to explain what they meant by stigma. LCA’s meaning of stigma is not exactly reflected by Erving Goffman’s traditional definition, “the situation of the individual who is disqualified from full social acceptance.” Goffman’s concept of stigma has been influential in defining the relationship between individuals and disease. His theoretical contributions have been widely discussed, critiqued and disseminated. Though

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the concept has changed over the past 50 years, Goffman’s formulation is still widely cited. Yet the audience understood what was meant by “stigma” in the campaign by mere common sense. No reference to Goffman or any other theoretical definition was necessary. Furthermore, the organization is not asking whether stigma exists, rather it is telling society that it has these attitudes, but we just have not examined them. LCA’s stigma framework actually indicates that a normative assessment has been made of the individual. He is not only disqualified, but also unworthy of social acceptance. In addition to implying the meaning of stigma, on the assumption that society has a common sense understanding of what stigma means, the campaign implicitly pushes for a response to these injustices that places the lung cancer patient in the medical frame. These areas of collapse (where the organization does not explain the concept or work that the concept signifies) allow LCA to tailor theoretical frameworks into a small, practically applicable, package and match them to tangible, but proxy, measures of injustice. LCA glosses over these important topics of social theory. I am interested in breaking LCA’s narrative apart to understand the complexities of stigma, medicalization, and the social interaction that contributes to both frames.

Identity-making and responsibility are a central focus of the 2012 Lung Cancer Alliance campaign. The campaign visually represents attitudes which LCA states are wrong. The visuals implicitly point to certain ways identity is constructed. These methods for identity construction are not explained. It is assumed the audience understands what they are and the common sense reasoning Lung Cancer Alliance is utilizing to state this method of constructing identity is stigmatizing. Given that Lung Cancer Alliance’s stigma narrative flattens out the relationship between disease, identity making and
responsibility, how is this relationship made? Put another way, by virtue of invoking the term ‘stigma,’ what can go unsaid? The stigma framework encodes normative judgment in the relationship between identity-making and responsibility. A stigmatized understanding of lung cancer is rooted in a public logic that inserts moral assessment into judgment of difference, as LCA implies. This kind of identity-making and attribution of responsibility is not specific to lung cancer. However, it is significant that this type of explanation exists for lung cancer. Such an explanation legitimates LCA’s call for medicalization of lung cancer since society strives for moral neutrality, especially in relation to disease. This is reflected in society’s emphasis on objective data and, in the medical frame, epidemiological explanations for disease. Public awareness singles out cigarettes as a major source of cancer-causing agents, or carcinogens. The social knowledge states that smoking = lung cancer = death. Carcinogens ingested mainly by smoking is a clear, discrete cause of lung cancer. Therefore, lung cancer is already medicalized. Yet, lung cancer is not intitially presented by LCA to the audience through statistics that empirically show the toll lung cancer takes on the population, including those who do not smoke. Instead, the disease is presented in terms of stigma, which is rooted in moral kind-making. LCA tells the audience that they view the disease with unjust preconceptions generated from negative identity-making. This could be understood as: stigma= unjust attitude= exclusion. LCA states that this is the wrong way to understand the disease and that there is a corollary relationship between the disease and social interactions that is the correct way to understand the disease. Given the aspiration toward moral neutrality, LCA implies that the medical frame is the correct frame within which to understand the disease by emphasizing a reform of the proxy measures of
stigma such as minimal federal funding, high mortality rate and low awareness. It is not a question of whether their proposed interventions are correct or incorrect. What is significant is that they have proposed this problem (a “stigmatized” understanding of disease) that they say represents injustice. Furthermore, the organization roots the injustice in failure of public responsibility toward the diseased. In order to decrease these secondary outcomes of stigmatized understanding of disease, LCA proposes the problem be medicalized.

The stigma and medical frames of disease surprisingly share several common methods for constructing the relationship between disease, identity and responsibility. Theorists of social interaction and medical sociology have shown that disease and health have long been a locus of moral identity. I have borrowed from this body of theory on stigma and medicalization, using these concepts as tools to provide an analysis of social relationships brought to the forefront by the “No One Deserves to Die” campaign. The moral character of the stigma framework bears on understanding of disease when comparisons of people and their behavior with unstated norms yield differences that can be blamed on the patient. Lung cancer is different from other cancers because the assumed difference is smoking, which is an irresponsible social behavior. As such, lung cancer patients are excluded, and their identity is largely assumed based on past demonstration of irresponsibility toward health. How, then, is the perspective of the problem of injustice toward lung cancer patients shifted by medicalizing the relationship between disease, identity-making and responsibility? The same types of social interaction attributed to the ‘unacceptable’ stigma frame also occur in the ‘neutral’ medical frame. In the medical frame, the patient becomes actively responsible for managing his disease.
Difference is assessed on this basis when the patient fails to carry out his patient role as expected. In order to maintain a positive moral identity in this frame, the patient is responsible for prioritizing his health in the manner in which the physician deems appropriate. The patient is only excluded, then, if he does not manage his disease properly. Therefore, identity is dependent on an active responsibility toward health. The moral vestiges that persist in the medical framework problematizes the cleanliness of medicalizing lung cancer completely, as implied by LCA.

This thesis uses the case study as an analytical tool to dissect the moral aspects of the disease frame. I begin in chapter one by providing a description of the case, Lung Cancer Alliance’s “No One Deserves to Die” campaign. In undertaking this study, I conducted a thorough examination of the campaign itself, and I reviewed the organization’s published educational and informational materials. These documents included fact sheets, press releases, the legislative bills and the Lung Cancer Alliance blog. I also conducted a phone interview with the Communications Manager for Lung Cancer Alliance (LCA). In chapter two, I go on to analyze important aspects of the case. I began with the case study and case analysis because the case is arresting yet the topics it emphasizes are not theorized. By organizing my discussion in this way, the thesis follows the progression of the story of Lung Cancer Alliance and the “No One Deserves to Die” campaign. Starting with the case provides a foundation describing society’s common sense understanding of the disease and of stigma. Proceeding from this basis, this thesis will then discuss what is hidden or overly simplified in the common sense understanding in order to bring a richer understanding of the features that made this case interesting and

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9 The interview questions discussed above can be found in Appendix C.
an important area for research. Therefore, the reader is lead into a theoretical discussion of the two disease frames LCA focuses on, the stigma (chapter 3) and medical frameworks (chapter 4), after the case discussion to be able to understand the theories with common background knowledge. These later chapters engage primarily with the theoretical literatures on stigma and medicalization theory. The literature I rely on includes a variety of books, peer-reviewed articles, and popular news stories. These were assessed and selected from various sources including online databases and citations in related literature based on relevance and contribution to the discussion at hand. LCA frames the problem of injustice toward lung cancer patients as a problem of stigma. The organization offers a solution in the form of medicalizing our understanding of lung cancer. Framing the disease in these terms influences identity-making and claims of responsibility. My aim is to use this case as an entyapoint into theoretical discussions that elucidate how disease, identity-making and responsibility interact in these frameworks.
CHAPTER 2
THE "NO ONE DESERVES TO DIE" CAMPAIGN

I. Introduction

The June 2012 “No One Deserves to Die” advertising campaign released by the Lung Cancer Alliance tells the audience that we hold preconceived notions about lung cancer patients, whether we have thought about it or not. As a result, lung cancer patients are excluded from funding and awareness which benefit other patients of other types of cancer. LCA measures this in terms of secondary markers, which it considers injustices experienced by lung cancer patients: low public awareness; minimal federal funding; low priority in Congress and government agencies like the National Institutes of Health and the Centers for Disease Control and Prevention; and low quality of care in screening clinics. In order to correct for these largely quantitative measures of injustice, LCA is pushing for medical solutions.

Lung Cancer Alliance (LCA) has constructed its own narrative about the situation of lung cancer patients. The nonprofit organization employs stigma as a method of understanding lung cancer. Not only does LCA present this to the audience as the wrong frame, but LCA assumes that the audience knows what this frame means. The common sense basis for this argument makes this case especially interesting as an analytical tool to understand the way society understands disease. The areas of rich theoretical knowledge that are flattened, or where the complexity is ignored, in order to make a simple argument are significant. It is in these spaces that the resulting argument ignores the theoretical work that informs how and where relationships between disease and society are made. By asking how stigma is operationalized in the Lung Cancer Alliance advertising campaign,
I will unpack the relationships that are flattened due to framing the disease in terms of stigma. The goal here is to address the call for better understanding of “the influence of culture on the definitions of disease and of disease in the creation of culture, and the role of the state in defining and responding to disease.”

In this chapter I will explain the campaign and the nonprofit organization’s unique position that provides a background for its unique narrative. I will examine the actor’s (LCA) efforts to fulfill its mission: “ending injustice and saving lives through an alliance of advocacy, education and support.” I am representing the story here as it is provided by LCA. The claims regarding ‘injustices’ to lung cancer patients, so named by LCA, are the organizations claims. I will neither support nor refute those claims here, as that is not the goal of this thesis. I provide evidence from a third party that supports the legitimacy of the organization as a non-profit which aims to aid patients, but this thesis should not be read as an endorsement the organization outright. This is not the proper forum to discuss any skepticism about the organization itself or its nomenclature of low survival rates or low awareness as ‘injustices.’ Rather, the goal of this thesis is to simply understand and analyze the stigma narrative LCA provides. The description of the case in this chapter will lead into a discussion in the next chapter about the actor/analyst role LCA plays in asserting that lung cancer is framed in terms of stigma, and discussion of their interventions leading to the call for a reformation of society’s understanding of lung cancer.

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II. “No One Deserves To Die”

The inspiration for this project came in June 2012 when the nonprofit organization Lung Cancer Alliance released the “No One Deserves To Die” campaign. The campaign was released as bus shelter, print, television, social media and online advertisements. Besides my previous interest in the social life of cancer, the campaign caught my attention, and indeed it was designed to do precisely this. The campaign is comprised of a collection of six arresting images, each depicting a different group of people defined by a single characteristic or feature. The pictured types of people are not individuals with lung cancer, but they are types of people who experience the same discrimination as individuals with lung cancer patients experience. For explanatory effect, Lung Cancer Alliance applies the same reasoning about the identity of an individual with lung cancer to other types of people to show that the exclusionary conclusions society reaches about lung cancer patients are non sequitur. For example, one image depicts a young man in clothing and accessories most commonly belonging to the popular ‘hipster’ style. The term hipster and the subculture it refers to carry varying connotations and could otherwise be characterized as ‘progressive’ or representative of independent thinking; regardless of the connotation, the goal of the visual is simply to present the outer appearance of this individual. The statement that he and others like him deserve to die is striking. I am perplexed; why do hipsters deserve to die? Based on the given information in the visual, the poster seems to assert that is that this particular individual deserves to die because of his hipster identity-- his outward appearance and stylistic affiliation with the hipster subculture. The hipster subculture carries certain

11 See Appendix A
connotations, and the group is commonly judged due to the superiority its members typically assert of themselves over others in mainstream culture. His outer appearance is a marker of the meanings behind this group. The campaign shows how this particular hipster is compared with others and considered different. His difference is being understood and ascribed a certain moral character. That moral character is deemed of lesser value, and is excluded. However, the conclusion that all hipsters are bad people and deserve to die is such a blunt, discriminatory assertion that counters our culture’s celebration of diversity and identity. Lung Cancer Alliance tells us this can be understood as stigma.

By design, the campaign ran without explanation for a full week; the public was only confronted with the attention grabbing line telling us that certain groups of people “deserve to die.”12 No further explanation was provided. The campaign received a strong reaction; the visuals became known as “the posters so provocative that people tore them down.”13 After one week had passed, the Lung Cancer Alliance (LCA) released more information regarding the intention behind the campaign.14 The viewer was directed to NoOneDeservesToDie.org where he would learn about lung cancer, the injustices faced by lung cancer patients (for which the organization blamed stigma), and the need for improved attitudes regarding the disease. LCA released a television advertisement at this point as well which helped explain the connection between the original judgment (someone “deserves to die”) and the message that society needs a new attitude about this

12 See Appendix A.
14 See Appendix B.
disease. The television ad depicts a woman at home, joyfully making clothing for her cat. After the scene unfolds, the text displayed on the screen asserts, “Cat lovers deserve to die… if they have lung cancer.” The voice- over then states, “Lung cancer does not discriminate; neither should you” and displays the website “NoOneDeservesToDie.org” and the organization’s name and logo.15

The goal of the campaign was twofold; first, to stimulate conversation, and second, to “reverse long held perceptions that people have about [lung cancer].”16 To do so, the text of the campaign was not only intended to be repellant, it was also intended to show that the audience harbors those feelings about lung cancer patients. The idea is that conversation would arise when the audience realizes previously its previously unappreciated moral judgments about lung cancer patients. Laughlin Constable, the advertising agency responsible for creating the “No One Deserves to Die Campaign,” clearly describes the theme of the campaign:

“Lung cancer is a disease, not a punishment. The No One Deserves To Die campaign used in-life teasers to seed the conversation in dozens of cities across the country, as the first step in ending the stigma associated with this, the number one cancer killer.”17

A large portion of the message of the campaign hinges on the visual representation of these 6 types of individuals in relation to the blanket judgment made in the overlay text about this type of person in the background. This interplay is meant to

mimic the thought process one undergoes when making a first impression and judgment about an individual. Lung Cancer Alliance uses this appeal to connect with the audience. In the process, LCA states public perception, formed by commonly held assumptions and practices, is in need of reform. In this way, visual presentation of a common thought process is meant to transition the viewer into reflection about his own attitudes. The overall intention was to provide society with a specific example of attitudes that it ostensibly harbors—attitudes that should be reformed. The logic behind the campaign is that by doing this work, generating internal awareness, individuals will be induced to discuss their personal observations with their peers; thereby, produce a conversation, and a national discourse about lung cancer. In so doing, awareness of the disease and awareness of the injustice that LCA calls stigma is raised. As wider discourse leads to reversal of common perceptions of the disease, the second goal of the campaign, exclusion felt by lung cancer patients would be diminished. The tangible, but secondary, injustices to this group can be reformed. Those injustices are measured by the LCA in various ways, including amount of federal funding, legislative action and level of care in the clinic. These will be discussed below. First, a description of the nonprofit organization helps legitimate their standing and explain why Lung Cancer Alliance is a group worth consideration.
III. Lung Cancer Alliance

Lung Cancer Alliance brands itself as the leading lung cancer activist group. They claim to be the “only nonprofit organization dedicated solely to support and advocacy.”\(^\text{18}\)

It was recognized as one of the “Top Nonprofits” by *Philanthropedia* in 2011\(^\text{19}\) and is ranked three out of four stars by *Charity Navigator*\(^\text{20}\), both of which are independent nonprofit groups that analyze other nonprofit groups’ financial and activist activities. It is significant that other activist groups also target lung cancer specifically, two of which also occupy top spots on *Philanthropedia.com* and *Charitynavigator.org*. All three fall under the the category for national organizations benefitting cancer; Lung Cancer Alliance is ranked #10, National Lung Cancer Partnership is ranked #12, and Lungevity Foundation is ranked #15 on the “Top Nonprofit” list in 2011.\(^\text{21}\) *Philanthropedia* ranks nonprofit organizations based on expert analysis which incorporates expert perception of nonprofit’s impact.\(^\text{22}\) Experts, including policy makers, researchers, academics, professionals, etc. are invited to recommend nonprofits in their area and answer a questionnaire to explain their recommendation and provide support for the organization’s impacts. Conflicts of interest are eliminated by excluding recommendations for nonprofits which the expert is professionally affiliated with.

\(^{21}\) See note 15.
Another site, Charitynavigator.org, assesses nonprofit organizations based on two major categories: 1.) accountability and transparency and 2.) financial responsibility. Accountability and transparency is assessed based on 17 points, which include the presence and accessibility of the organization’s policies such as the whistleblower and donor privacy policies. The organization’s financial responsibility is assessed based on data obtained from the organization’s published Form 990 disclosing the organizations’ financial breakdown providing information such as expenses, gifts and contributions, revenue growth, administrative expenses, and CEO salary. These are graphed together producing a number out of 70 combining both measures and an overall score. Lung Cancer Alliance received a 58.14/70 and three out of four stars as of fiscal year-end in December 2012.23 National Lung Cancer Partnership received a 56.89/70 and three out of four stars as of fiscal year-end in December 2011.24 LUNGevity Foundation received a 59.58/70 and three out of four stars as of fiscal year-end in June 2012.25

By these measures the top nonprofits are nearly identical. All three are legitimate nonprofit organizations with a wide scope of national support and funding. Each organization is aiming to make a large scale impact. However, the focus of each group

differs greatly. This can be summarized most clearly through their stated missions and visions. Each articulates the goal to reduce lung cancer mortality, or number of deaths, in either the mission or vision statement. National Lung Cancer Partnership emphasizes “research, awareness and advocacy” to achieve this goal by 2022.26 Lungevity Foundation’s stated vision is “a world where no one dies of cancer,” and aim to achieve this vision by emphasizing “quality of life…survivorship…, early detection, and support.”27 Lung Cancer Alliance’s mission is “ending injustice and saving lives through an alliance of advocacy, education and support;” their vision is to reduce lung cancer mortality to 50 percent of it’s current rate by 2020.28 Lung Cancer Alliance’s goal of “ending injustice” places the organization in a unique position as the only one of its class directly aiming to reduce injustice, identified in terms of stigma, surrounding the disease. LCA differs from the other two organizations in that it frames the core problem of lung cancer as being the product of social marginality, and explains the marginality of the disease in terms of stigma. Thus LCA’s mission to mitigate marginality by enacting destigmatization. Destigmatization, to LCA, means reframing public perception of lung cancer in terms of medicine and biomedical research. This shift would transform the problem from a social and moral problem into a purely medical problem. It is the centrality of the notion of stigma, and the corollary of destigmatization as medicalization that makes this group an interesting focus for this case study.

Lung Cancer Alliance is a non-profit organization based in Washington D.C. and is the largest lung cancer advocacy group in the world. Lung Cancer Alliance (LCA) was founded in 1995 under the name Alliance for Lung Cancer Advocacy Support and Education (ALCASE). In 2005, LCA established headquarters in Washington D.C., and in 2012, established the Lung Cancer Alliance National Advocacy Advisory Council in addition to the medical and professional advisory board and honorary board it has assembled. The CEO, Laurie Fenton Ambrose and Chairman T. Joseph Lopez sit on the National Advisory Council, in one of the organization’s most recent efforts to address Lung Cancer Alliance’s national goals. LCA’s reported mission is “ending injustice and saving lives through an alliance of advocacy, education and support;” their vision is to reduce lung cancer mortality, or number of deaths, to 50 percent of it’s current rate of roughly 160,000 per year by 2020.\(^{29}\) LCA aims to achieve these goals by addressing under-represented problems at all levels of society. These levels are represented by LCA’s three programs. First, they support individuals with lung cancer by offering individual help through the Community Outreach and Support Services Program; second, they advocate specifically for lung cancer research and related policy action in the legislature via the Health Policy Program; and, third, through National Awareness Programs. These include *Give a Scan*, *Team Lung Love*, and the *National Shine A Light on Lung Cancer Vigil*, specifically intended to “empower[sic] families to help eliminate stigma.”\(^{30}\) In addition, LCA has released several national awareness campaign aimed at a

\(^{29}\) Lung Cancer Alliance. 2012a. “About Us.”

\(^{30}\) See Note 25.
more general audience via the “No One Deserves to Die” campaign and the subsequent “Moments” campaign.

IV. Measuring Injustice

Lung Cancer Alliance represents the diminished status of lung cancer in the eyes of society in several ways, as stated previously. During a phone interview with the Communications Manager at LCA, we discussed the difficulty with measuring stigma and successes in confronting stigma. I asked her how Lung Cancer Alliance determined stigma was a problem, and how the organization measured this problem. She responded by saying the organization had not measured stigma directly. Tellingly, she instead offered examples of indirect indicators. She said that LCA seeks to impact change by increasing federal funding for lung cancer-specific research; by passing legislation that will fund plans to improve 5-year survival rates of cancers with less than 50 percent survival rate; and by improving standard of care for the at-risk and patient population. Though we did not directly discuss the parallel with breast cancer apparent in other materials, her discussion of the low 5-year-survival rate indicated that the current statistic, placing survival rate just below 16%, could be improved by following the breast cancer model. Improvement of the 5-year-survival rate for breast cancer is correlated with increased federal research funding and preventive screening according to LCA’s published educational materials.\(^\text{31}\) The implication is that if the public perception and attention is supportive, medical interventions provided by more funding, and better care will follow, as it did with breast cancer. In addition, the website and LCA news has a

\(^{31}\) See Note 25.
heavy focus on legislative action. Given these discrete manifestations of injustice, it becomes easier for LCA to mark the “No One Deserves to Die” campaign as a success. In providing tangible harms that can be corrected, LCA is saying that society will know lung cancer has been destigmatized when it is given the medical and research attention it deserves. The more interesting parallel story describes society shifting its perception about individuals with lung cancer in such a way that the disease is separated from the individuals’ moral identity.

Lung cancer is the second leading cause for death in the United States with a 5-year survival rate of only 15.9 percent.\textsuperscript{32} The National Center for Health Statistics reported that in 2009 158,158 people died of lung cancer, second only to heart disease which accounted for the death of 599,413 people in the same year.\textsuperscript{33} The National Center for Health Statistics reported that in 2009 158,158 people died of lung cancer, second only to heart disease which accounted for the death of 599,413 people in the same year.\textsuperscript{34} 28,000 of those who died had never smoked; LCA repeatedly reports that 80% of new lung cancer cases occur in former smokers or those who have never smoked. LCA feels that the continuing high impact of lung cancer is both an injustice to patients and a result of unmitigated injustices in multiple sectors. The organization attributes low survival rate and high mortality to minimal federal funding, restricted discourse about the disease due to stigma and inadequate options for screening and quality care.

In the “2012 Lung Cancer Facts” Sheet, the LCA reports that lung cancer research receives federal funding from the Department of Defense, the National Institutes of

\textsuperscript{32} See Note 25.
\textsuperscript{33} See Note 25.
\textsuperscript{34} See Note 25.
Health and the Centers of Disease Control. However, the total commitment of research dollars is only $231.2 million. Furthermore, lung cancer research received fewer dollars per death in 2012 ($1,442) than it did in 2005 ($1,871). On the Fact Sheet, LCA asks, “Why is the survival rate for lung cancer still so low?” They answer this question right below: “because so little federal funding is committed to lung cancer research.” Though fluctuations in funding for lung cancer are small in comparison to the final per death expenditure, LCA implies that the fluctuations are representative of the low amount of national attention the disease receives. The question that follows, then, is: “why is federal funding still so low?” LCA is implying on the Fact Sheet and explicitly states elsewhere that the problem of injustice for lung cancer patients is because we understand the disease to be stigmatized. The organization supports the claim that lung cancer is treated as a second rate disease and is underfunded as a result of stigma by comparing statistics regarding other cancers with high mortality rates. Of the four leading causes of cancer deaths (lung, colon, breast, and prostate cancers), lung cancer receives the least funding across the board. On the fact sheet, LCA have published statistics showing federal funding for breast cancer was about $1 billion dollars in 2012. Despite the fact that breast cancer is the 11th leading cause of death and has a 5-year survival rate of 89.0 percent. In 2005, breast cancer received $25,635 per death; in 2012 it received $26,398 per death. The most poignant comparison on the sheet is a graph depicting today’s lung cancer 5-year survival rate (15.9 percent) with that from 1974-1976. The disparate progress made in treatment is most apparent in the increase of the 5-year survival rate for breast cancer from 75 percent in 1974-1976 to 89.0 percent in 2002-2008. This increase represents the sharpest contrast with lung cancer, for which the 5-year survival
rate has increased to 15.9 percent in 2002-2008 from only 13 percent in 1974-1976. This specific graph aims to represent the gains made from advanced research over roughly the past 30 years. The implication is that federal funding directly affects the improvements in mortality and 5-year survival rates. In contrast to lung cancer, breast cancer research receives more federal dollars per death today ($26,398) than it did in 2005 ($25,635). Overall, lung cancer research only receives 22 percent of the yearly research funding breast cancer receives ($1,043,000,000). The LCA’s argument is that lung cancer is underrepresented in terms of funding compared to the attention due to the disease based on the high mortality rate and low 5-year survival rate. The purpose of the fact sheet is to support this argument by presenting statistical data in order to create an understanding of the climate surrounding lung cancer and comparing that data with that of other common cancers. By showing that those cancers with the most funding have made the most progress in 5-year survival rate, LCA has illustrated their argument for the need for increased funding. The organization supports this conclusion with the statistics that show the gains made in terms of mortality rate due to high levels of research funding. LCA’s influence in legislative action and in improving health care practices can be discussed in terms of residual impacts of the “No One Deserves to Die” campaign. These conclusions are the Lung Cancer Alliance’s conclusions; I am transcribing them into words here to help explain their argument. Again, this is not an endorsement of their measurement or use of the term ‘injustice;’ this section simply serves to retell the story LCA told in the “No One Deserves to Die” campaign.

In the next section I will provide a brief discussion of the public action that occurred after the “No One Deserves to Die” campaign which LCA provides as evidence of the impact of the campaign. This discussion is provided to contextualize the campaign. Though the project here is not to assess the efficacy of the campaign, it is useful to understand the secondary markers of success LCA is using to self-assess their successes. This discussion will provide a broader view of the case as it is situated in society. From this background, we can move on toward understanding the campaign and LCA’s vision for how disease ought to be framed.

V. Impacts

In our interview, Ms. Geier, Communications Manager for Lung Cancer Alliance, stated the first week of the campaign was successful in achieving the first goal of the campaign: to stimulate conversation. She stated this was exhibited when the campaign became the 2nd most popular story on Yahoo.com that week. Furthermore, the noonedeservestodie.org website received 150,000 visitors looking for information during the first week; Geier interprets this increased traffic as an increased opportunity for education, which she identified as a key feature of this approach. She explained that the campaign was released in 31 key markets which were chosen based on population density, the intent being to reach as many individuals as possible. Though Geier stated 97 percent of conversation about the campaign was positive, the Yahoo News story

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references mixed responses during the first week of the campaign. From LCA’s perspective, people were talking about the campaign and their message.

Following the “No One Deserves To Die” campaign, the LCA has seen other impacts that could reflect changing perceptions of the disease. In the eyes of the advertising community, the campaign was highly creative, effective and impactful. The campaign received the Bronze Effie award and Silver OBIE for Public Service award for the campaign in 2013.\(^{38}\) The Effie award is a national and international award given by Effie Worldwide, a nonprofit organization; it marks excellence, with special attention to effectiveness, in marketing.\(^{39}\) The OBIE award is given by the Outdoor Advertising Association of America, and awarded by peers in advertising, for creative excellence.\(^{40}\)

A larger impact of the campaign was felt in the policy arena by the passage of a key piece of legislation: the Lung Cancer Mortality Reduction Act of 2011. Senate Bill S752, The Lung Cancer Reduction Mortality Act, additionally states, “(8) Lung cancer is the most stigmatized of all cancers and the only cancer blamed on patients, whether they smoked or not.”\(^{41}\) President Barack Obama signed the Recalcitrant Cancer Act, a combination of the Lung Cancer Mortality Reduction Act and another bill aimed at achieving similar goals for pancreatic cancer, into law in January 2013. The Lung Cancer Mortality Reduction Senate bill was originally sponsored by Dianne Feinstein (D-CA),


\(^{41}\) 112\(^{th}\) Congress of the United States of America. 2011. S. 752.
Sam Brownback (R-KA), Hillary Clinton (D-NY) and Chuck Hagel (R-NE). On its third introduction in the 112th Congress, Senate Bill S752 was again sponsored by Feinstein, with the addition of Johnny Isakson (R-GA) and John Kerry (D-MA). On their website, LCA announce that their goals for the legislation, to make lung cancer a priority and garner bipartisan and bicameral support, were met with great success. Provisions for House Bill H.R. 1394 and Senate Bill S. 752 found their way into law during 112th Congress as an amendment to the National Defense Authorization Act for Fiscal Year 2013, H.R. 4310 Sec. 1083 “Scientific Framework of Recalcitrant Cancers.” Based on the facts as presented, the Senate made lung cancer a “national public health priority” and endorsed creation of a Health and Human Services directed mortality reduction program. The program directly addresses LCA’s goal to reduce lung cancer mortality rates by 50 percent by year 2020. To achieve this, the Act authorizes funding for research and outreach. The National Institutes of Health, Food and Drug Administration, Centers for Disease Control and Prevention and others are specified in the Act, each with unique requirements for creating their programs. These requirements include funding research regarding: the interrelation of diseases; screening and interventions for lung cancer; environmental factors contributing to incidence of lung cancer; and prevention and outreach efforts. These categories are made specific depending on the agency. The Act also makes provisions for establishing the Lung Cancer Screening Demonstration Project, aimed at improving screening and care for those at risk. This project has 180 days to

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report the budget and will be conducted over the next five years. This section also codifies efforts made by the LCA for official screening center certification. Finally, the Act establishes the Lung Cancer Advisory Board, which will include members from Health and Human Services, the Secretary of Defense, the Secretary of Veterans Affairs, the Director of the Occupational Safety and Health Administration, and the director of the National Institute of Standards and Technology, in addition to medical and scientific experts, advocates and the pharmaceutical industry representatives. The Act is directed specifically at the secondary measures of injustice cited by LCA. As passed, it refers to “recalcitrant cancers,” defined as “a cancer for which the 5-year relative survival rate is below 50%,” thereby including several types of cancer, including lung and pancreatic cancers. In this way, LCA was successful in obtaining a “response [from Congress] to reduce lung cancer mortality in a timely manner.”

Another impact of the campaign was closer to the ground level in the form of the United States Preventive Services Task Force (USPSTF) official recommendation of low-dose computed tomography (CT) screening. Approved for people 50 years of age and older, the screening was approved as a measure to catch and intervene on lung cancer earlier in its progression. Recently, the National Lung Screening Trial (NLST) study confirmed the efficacy of the screening test by showing a 20 percent reduction in deaths due to lung cancer and cost efficiency of the screening for the patient and the nation.

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The Lung Cancer Alliance has published the National Framework For Excellence in Lung Cancer Screening and Continuum of Care to establish a uniform standard of practice for health care professionals providing care to lung cancer patients. The Framework as published at this time does not specify low-dose CT screening; however, it will likely be revised when the USPSTF recommendation is finalized at the end of this year.47 Ms. Geier also mentioned the LCA’s continuing effort to urge private insurance companies and the Centers for Medicare and Medicaid Services recognize the screening recommendation and ensure low-dose CT screening. The LCA’s goal here is to reduce obstacles to access by ensuring insurance coverage. With such improvements to screening and screening centers, wider access to screening and appropriate, compassionate treatment is another result- in- progress of the campaign that LCA provides as evidence of success of their campaign.

According to LCA, progress is being made to improve these secondary measures of exclusion and injustice. This progress is what LCA envisions the process of destigmatization to look like. From the organization’s perspective, it has made strides in altering public perception of lung cancer. Now that more attention has been given to lung cancer, LCA has released the next step toward tackling exclusion and injustice in the form of a new campaign, called “Moments.”48 This campaign does not directly tackle stigma as the “No One Deserves to Die” campaign did. Rather, “Moments” emphasizes risk awareness. The basic approach for this campaign is similar to “No One Deserves to

Die:” to reach as many viewers as possible and get people talking. LCA hopes this new campaign will go beyond stigma, and encourage those at risk take action by getting screened for lung cancer. In addition, LCA hopes to encourage friends and family members of an at-risk individual to open a dialogue about lung cancer and screening. This new campaign serves as a transition toward medicalizing public perception of the disease. “No One Deserves to Die” confronted previously unacknowledged public perception, called stigma. Now that hidden norms have been brought to the forefront, LCA is now able to encourage people to think about how the disease touches their own lives. Furthermore, they encourage society to act on it as the medical problem that it is, rather than the moral problem we previously thought it was. Lung Cancer Alliance’s overall argument emerges from this description as medicalize public perception to destigmatize public perception of lung cancer.
CHAPTER 3
DISSOCIATING THE DISEASE FROM THE DISEASED: CASE ANALYSIS

“At the heart of their objection is the belief that no society can be regarded as socially just if it permits the stigmatization of certain of its minority groups.”
- Robert Page, *Stigma* 49

I. Introduction

Lung Cancer Alliance’s mission is “ending injustice and saving lives through an alliance of advocacy, education and support.” 50 The most recent effort to fulfill this mission, the “No One Deserves to Die” advertising campaign, was simple, although its message was anything but simple. The campaign was able to communicate complex ideas through just a few words and pictures. The fact that Lung Cancer Alliance could release a campaign that called the injustice experienced by lung cancer patients “stigma” and expected society to understand what it means without definition is significant in two ways. First, Lung Cancer Alliance is not merely proposing the existence of stigma. LCA is telling the public on no uncertain terms that stigma (negative stigma) is attached to lung cancer, and that it is causing negative outcomes for the lung cancer patient. Second, LCA is treating federal funding and clinical care statistics as a proxy for measuring stigma. These particular proxies are tied to public perception and public institutions that reflect stigma in their response to disease. More federal research funding, better patient care and more awareness help shape LCA’s picture of what lung cancer would look like

if it were destigmatized. LCA’s focus on these secondary measures indicates that it has a vision for the *right* construction of public attitudes about disease. Furthermore, these proxies indicate the group is emphasizing that the moral implications on the lung cancer patient’s identity be removed. The lung cancer patient should be thought of as a *patient*, not a deviant. In Lung Cancer Alliance’s construct, progress means moving away from understanding this disease in terms of stigma toward understanding it in medical terms. In the medicalized experience of lung cancer, without stigma, LCA envisions these patients would enjoy inclusion, awareness and care equal that of other cancers. In addition to asserting that stigma exists, LCA is making an implicit assessment about responsibility. To counter the notion that an individual patient is responsible for causing the disease, the campaign message asserts that larger society is responsible for assigning the lung cancer patient the status as ‘different’ from other cancer patients. LCA’s shift of responsibility onto society echoes Susan Sontag’s assessment of the modern discourse of the “disease metaphor” which “assume[s] a punitive notion: of the disease not as a punishment but as a sign of evil, something to be punished.”\(^{51}\) Thus, society is responsible for constructing an identity for the individual with lung cancer that stigmatizes him, casting the lung cancer patient’s identity in a negative light. The primary goal of the “No One Deserves to Die” campaign is to make viewers become aware of their own latent attitude about lung cancer and lung cancer patients. Through this medium, the audience is not asked whether they have a negative attitude; they are *told* that they do in fact hold a negative attitude toward the disease and the patient, but it is simply an attitude they have not interrogated. Through the “No One Deserves to Die” advertising campaign, stigma is functioning as a

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way for Lung Cancer Alliance to frame society’s understanding of the disease. Within this framework, or set of assumptions and practices, they are able to explain the problems lung cancer faces in a narrative of exclusion and injustice, emphasizing society’s responsibility for these consequences. Using stigma as a way to tell this story also asserts a corollary vision of the right relationship between disease, identity and responsibilities of a society. The “No One Deserves to Die” campaign points to larger society as the party responsible for holding negative attitudes about lung cancer patients. The implication of the campaign is that it is society’s burden to change these negative attitudes. LCA indicates that the problem lies in society, as it is not the lung cancer patient’s responsibility to change society’s attitudes. The fact that the campaign has had impacts in the legislature (passing the Recalcitrant Cancer Act) and clinic (approval of low-dose CT screening) demonstrates that the stigma frame was effective at constructing a narrative that tells the audience that stigma causes exclusion and injustice. It is more difficult for society to refute LCA’s claims since it offers proxies for stigma that can be measured. Based on statistics alone, LCA’s argument that the situation warrants change seems reasonable. The audience received the message loud and clear from this ostensibly minimalist campaign. “No One Deserves to Die” touched a cultural nerve. Given these observations about the campaign, how is stigma operationalized in the Lung Cancer Alliance advertising campaign?

II. A Brief Review of the History

Lung cancer is a disease that deserves special interest because its historical context makes it a different kind of cancer. I will provide a brief overview of the history
of smoking to provide a contextual background for the case. Then, in the following sections of this chapter I will offer my analysis of the case as described in the previous chapter. I will then deepen this analysis by providing theoretical discussions of the two main frameworks discussed by LCA in chapters 4 and 5.

Allen Brandt offers an in-depth study of the history of smoking in America in *The Cigarette Century: The rise, fall, and deadly persistence of the product that defined America*. His book offers discussion of the nuances of what it meant to smoke in America. The historical account provide a strong basis for the set of common assumptions society holds today about smoking and about lung cancer. Beginning from the cigarette as a product of labor he traced its transformation into a product exemplifying mass consumerism. Brandt discussed the act of smoking as a frame for the identity of those who could be included as consumers. He also discussed the cigarette as an object around which a large amount of knowledge-making was centered, becoming a locus of individual responsibility, especially in relation to health in both medical and legal frames. Much of Brandt’s expertly crafted history of this topic is beyond the scope of this project but provides an important background understanding of the social context that forms the basis for today’s understanding of the meanings of lung cancer.

In his expert testimony in *United States v. Philip Morris* (2003), Brandt explained that clinical, experimental and population-based knowledge contributed to the understanding of health effects, especially lung cancer causality, in the 1940s and 1950s. He explained that the exchanges between these sectors made consensus

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regarding the link between smoking and lung cancer an elusive goal. In his book, Brandt
depicts his testimony as a drop in the bucket of reports contradicting each other about
knowledge of lung cancer causality and the link between smoking and adverse health
effects during that period of time. Despite the rampant contradictory testimonies in this
case, Judge Gladys Kessler ultimately ruled in 2006 that Philip Morris, and the tobacco
industry as a whole, had violated the Racketeering Influenced and Corrupt Organizations
Act of 1970 (RICO)

“by suppress[ing] research, … destroy[ing] documents, … manipulate[ing] the
use of nicotine so as to increase and perpetuate addiction,…and… abus[ing] the
legal system in order to achieve their [the tobacco companies’] goal—to make
money with little if any regard for individual illness or suffering, soaring health
care costs, or the integrity of the legal system.”

The finding was precedential; however, Brandt and Kessler both bemoan the fact that this
ruling could not produce a lasting effect, beyond altering marketing practices, as Kessler
was unable to assign punitive action.

Today, the link between smoking and lung cancer is no longer contested in the
public understanding of the disease. As early as the 1970s, anti-smoking campaigns
began emphasizing health risks and discouraging smoking. Multiple lawsuits, especially
the early class action suit Engle v. R.J. Reynolds (1999), attempted to place responsibility
for health problems with tobacco companies due to false advertising, rather than with the
individual. The medical community has recast smoking as a nicotine addiction treatable

53 Quoted by Brandt, Brandt. 2007. The Cigarette Century, 503; cited from United States
55 Ibid., 286
with pills and patches. The transformation of smoking from the cultural norm, and a common feature of a consumer society, to a nicotine addiction, and thus a treatable disease, is recent. Anti-smoking activism has been successful in re-casting the smoker’s identity; the modern smoker is no longer a consumer of a national product, but a deviant who, flying in the face of medical knowledge, chooses to accept the risk of developing serious health effects as a result of his smoking behavior. This serves to contextualize the basis for the stigma framework for understanding lung cancer. Society views the lung cancer patient as a smoker. The lung cancer patient is irresponsible for smoking and is risking his health, via society’s reasoning. Yet, the majority of the patient demographic is made up of individuals who have quit smoking (about 60% of patients) or were never smokers (about 18% of patients).\textsuperscript{57}

III. Social Reasoning

As a cancer, lung cancer is expected to be a “disease of the individual,” according to Susan Sontag.\textsuperscript{58} However, lung cancer, and its social meaning, is situated in the specific context of smoking. Susan Sontag states, “metaphorically, cancer is not so much a disease of time as a disease or pathology of space. Its principle metaphors refer to topography… and its most dreaded consequence, short of death, is mutilation or amputation of part of the body.”\textsuperscript{59} As a result, lung cancer is actually a disease of a perceived group of smokers. Significantly, this is a group that actively participated in the (previously very common) cultural behavior of smoking, which directly affects the lungs.

\textsuperscript{57} Lung Cancer Alliance. 2012e. “2012 Lung Cancer Facts.”
\textsuperscript{58} Sontag, Susan. 1978.\textit{ Illness as Metaphor},\textsuperscript{59}
\textsuperscript{59} Ibid., 14-15.
The individuals of the group are now subject to the consequence of lung cancer due to participation in the smoking group. Lung cancer patients as a group retain the ‘irresponsible’ label attached to the smoking group. As such, they have become a group identified as a group unworthy of care, as they are personally responsible for their disease. It is in this way, LCA argues, that lung cancer patients are stigmatized. It is equally significant that this is not a perceived group of people who breathe polluted air, or are subject to some other common feature of society such as exposure to asbestos that has negative effects on the lungs. LCA does not directly address or fight against smoking, pollution, or exposure to asbestos. It simply advocates for tolerance for patients who were exposed to these carcinogens.

Society has adopted the simplified understanding that smoking leads to lung cancer. Lung cancer is the disease most strongly correlated with smoking despite the fact that it is well documented that smoking is strongly correlated, if not a major causal factor, with several other diseases as well, including heart disease. However, those connections are not emphasized as often as the connection between lung cancer and smoking. Heart disease has a very different disease profile and the link between smoking and heart disease is complicated by diet and exercise. Thus, the linkage cannot be reduced to ‘smoking equals heart disease’ and ‘heart disease equals death.’ Not only would there have been too much information to impart, but the scattered effects would have reduced the focused attention to the body that lung cancer provides. The message that smoking

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60 For further supporting data, refer to Hecht’s endnotes. Hecht, Stephen S. 1999. “Review: Tobacco Smoke Carcinogens and Lung Cancer.” *Journal of the National Cancer Institute.* 91(14), 1210
has negative effects on one’s health would have become less focused. Connecting lung
cancer with smoking, however, provided a very focused message. Because of this, the
linkage between smoking and lung cancer was able to be extremely simplified. The
equation reads:

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\text{smoking} = \text{lung cancer} = \text{death}.
\]

It may be the case that this statement was constructed to be simple and easy to remember
in order to give it traction in the public consciousness. The obvious intention of such an
equation is to ultimately discourage smoking by connecting it with negative
consequences (the ultimate, negative consequence being death). A visual representation
as above shows that lung cancer is a transition state so to speak. As such, lung cancer was
deployed as a framework, or a set of common assumptions, for understanding the
relationship between behavior and health. This type of reasoning also maintains the moral
aspects of the disease in tact. The simplicity of the equation, and supposed simple
narrative of causation very likely contributed to its longevity in the public memory. This
narrative of causation served as the hub for a large-scale public health campaign, placing
more weight in this disease framework.

The downside of the simplicity of the message is that it flattens out diversity and
falsely ascribes simplicity to lung cancer. The true identity of the lung cancer patient is
not reflected by the idea that smoking equals lung cancer, thus lung cancer equals
‘smoker.’ Lung cancer, as the Lung Cancer Alliance states, can be traced back to
environmental factors since 17.9 percent of lung cancer patients have never smoked.\(^6\)
This portion of the group is especially invisible as they are grouped in with ‘previous

smokers’ and denied rights as if they too were previous smokers. All the while, the cause of their disease goes unaddressed. However, these individuals suffer from the same biological disease and experience the same ‘injustices’ (labeled as such by LCA) as other lung cancer patients in the form of minimal federal funding for research and advancement.

The diminished increase in 5-year survival rate, and low general awareness of lung cancer are equally influenced by factors beyond federal funding. The marginalization of the disease as represented by minimal funding and successes is due to low national awareness, activism, and political action. In contrast, other cancers, such as breast cancer and colon cancer, which have much greater national awareness and support, higher 5-year survival rates (lower mortality rates) and enjoy a larger allocation of federal funding, according to LCA. The injustices of decreased funding and 5-year survival rate that has only had marginal improvements are rooted in lung cancer’s association with smoking. In a video discussing the “No One deserves To Die” campaign, Michael Jeary, President of Laughlin Constable, the advertising agency responsible for the campaign, explains the issue. He states that the problem with “associating tobacco, smoking, with lung cancer is that it allows people to dismiss the disease.” The conflation of smoking and lung cancer marginalizes the lung cancer patient group. This is problematic in that it ignores a large proportion of individuals who die of lung cancer and had never smoked. The “We Are Lung Cancer Alliance” video discussing the campaign explains that 80 percent of those diagnosed with lung cancer either never smoked or have

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quit smoking.\textsuperscript{63} LCA emphasizes the holistic 80 percent statistic in the video, whereas in the Fact Sheet, the statistic is broken into its parts, stating that in fact 60 percent of those with lung cancer were former smokers and 17.9 percent had never smoked.\textsuperscript{64} The activist group does not aim to emphasize smoking behaviors, except to illustrate that lung cancer occurs in non-smokers and therefore, understanding the disease within the stigma framework is especially harmful to the 17.9 percent with claim to environmental causes. In fact, smoking behavior is secondary to the main argument, as understanding lung cancer within the stigma framework is harmful to all lung cancer patients who are in need of support, regardless of the presence/absence of personal causative behavior.\textsuperscript{65} The “No One Deserves to Die” campaign was intended to confront this unexamined attitude on the national scale.

IV. Looking at the Areas of Collapse

Lung Cancer Alliance’s “No One Deserves to Die” campaign is deceptively simple. The materials presented to the public are clean and represent a unified message. The message can be summarized as follows: ‘despite the appearance of a moral difference, lung cancer patients are like any other cancer patient; those individuals deserve care and support rather than exclusion. Exclusion from access to treatment and support stems from society’s attitude about lung cancer, so society needs an attitude adjustment.’

\textsuperscript{64} Lung Cancer Alliance. 2012e. “2012 Lung Cancer Facts.”
\textsuperscript{65} Gabriele Geier. “Personal Communication” November 8, 2013.
The campaign actually deploys ‘stigma’ as a common understanding of disease to tell a story of injustice toward individuals. This stigma framework refers to a certain set of assumptions and practices. Stigma as a framework attributes negative individual experiences to public attitudes. The connection of these attitudes with stigma is a significant connection because it characterizes these attitudes as inappropriate and unjust. Lung Cancer Alliance’s statements indicate that lung cancer patients are unjustly judged to be morally inferior due to society’s assumption that they have directly caused the disease from which they are suffering. Given the known risk of smoking, documented in the form of the Surgeon General’s warning since 1964 and suspected since the 1920s, today’s lung cancer patients are deemed the responsible agent for their disease. This is a unique situation. Few other cancers are understood in these terms. Since cancer is considered today as the result of a genetic mutation, the lung cancer patient is different because he is not the victim of a random biological accident but rather the major cause himself. The Lung Cancer Alliance’s argument is that difference, in terms of the patient’s role in the disease process, is judged by society and used as a vector to decide which claims the individual can make on society. LCA frames this phenomenon as stigma. LCA posits that this kind of exclusion, called stigma, has measurable negative effects. In a society that does not stigmatize lung cancer, those suffering from the disease would enjoy the benefits of more extensive scientific research; symbolic and financial support of the legislature; better access to early, low-dose computed tomography scans; and better overall care. As LCA pushes for change in society’s attitude about the disease,

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the organization is also pushing for a different conceptualization and a new set of assumptions about what social and moral relationships the disease frame should encode. By emphasizing the patient aspect of the lung cancer patient’s identity and asking for society to understand individuals in this group in the same way as they understand any other individual with cancer, LCA is attempting to medicalize the disease. Their overall task is to shift lung cancer out of the stigmatized frame into the medical frame. However, what this actually means is flattened out by the simplicity of the campaign. While these tasks are implied by LCA’s campaign and supporting materials, they are never fully articulated, theorized, or explained.

In achieving its goals, the Lung Cancer Alliance’s campaign actually has three stages. In order to change perceptions, the campaign first has to identify the problematic perception leading to the exclusion of lung cancer patients. That perception and attitude is then proscribed and, finally society is instructed to view this group in a different manner, which I will call dissociating the disease from the diseased.

To satisfy the first requirement, the campaign frames the viewers’ understanding of lung cancer in terms of stigma. The campaign materials do not define stigma explicitly; the LCA Communications Manager states “We don’t have an explicit definition for ‘stigma.’ It’s the negative reputation that has lived with lung cancer for so long. It is a mark of disgrace or infamy; a stain or reproach.” Furthermore, the organization does not need to define stigma for the audience; it (correctly, given the impact of the campaign) assumes society has a working understanding of the implications of the concept. LCA paints the picture that society has a common-sense understanding of

lung cancer through the lens of difference and exclusion. This form of conceptualizing disease is the result of a common thought pattern in ‘normal’ society. The common reasoning pattern begins with comparisons between individuals or types of individuals that leads to a judgment of difference and allocation of a moral identity and rights based on those differences. The campaign makes it clear that it is wrong for the ‘normal’ viewer to have a negative attitude regarding a lung cancer patient’s sick status. As the focus of the campaign, this attitude is identified as a primary obstacle preventing progress in treatment and prevention of lung cancer. It is significant that public attitude is targeted in this campaign, shifting both the locus of responsibility and moral failure away from the patient and onto society. The “No One Deserves to Die” media materials present a clean presentation of the logical analysis, identity-making and categorization process that individuals in society often undertake when confronted with a new situation or re-assessing a familiar one. In LCA’s formulation of the stigma frame, to pass judgment on a person with lung cancer is to inappropriately make a moral judgment regarding a situation that is less cut-and-dry than it appears.

A large body of epidemiological data shows that smoking causes lung cancer.\textsuperscript{69,70} Many associate this fact with the idea that a single, clear cause for the disease exists. This idea, in addition to the fact that the cause is 100 percent avoidable, creates the public perception that the smoker is consciously, flagrantly ignoring the health risk. As a result of irresponsibility towards one’s own health, his actions do not warrant special consideration should negative consequences arise. It is his own fault if he gets lung

\footnotesize{\textsuperscript{69} See Note 56. \\
\textsuperscript{70} Kleinsmith, Lewis J. 2006. \textit{Principles of Cancer Biology}, 69-72}
cancer. Furthermore, lung cancer has been a difficult disease to treat for many reasons, making the diagnosis of lung cancer equal to almost certain death. Following this logic, many have arrived at the conclusion: if one smokes and gets lung cancer, he deserves to die.

The deductive reasoning leading to this conclusion may stem from the psychological hypothesis of illness, as described by Susan Sontag, which states that people become ill “because they (unconsciously) want to” become ill.\textsuperscript{71} It is by will that the individual has chosen to become sick; such an individual, who has caused his own disease and willfully become a burden on others, deserves to be sick. The public logic expands on this hypothesis of illness and asserts that not only is this individual’s behavior the cause of the illness that he \textit{deserves}, but also that he deserves to die for making this irresponsible psychological choice. Sontag explains that, “with modern diseases,… the romantic idea that the disease expresses the character is invariably extended to assert that the character causes the disease- because [the character] has not expressed itself.”\textsuperscript{72} If his will is to smoke, he cannot be redeemed from the almost inevitable death sentence of lung cancer because of the irresponsibility and immorality of his decisions, which is a direct reflection of his core self.

The “No One Deserves to Die” campaign mimics this type of deductive reasoning by applying injustice and difference to an arbitrary characteristic. In the situation constructed by the campaign, the viewer is making an initial assessment of the person by observing his/her appearance, behavior and general demeanor. For example, the viewer

\textsuperscript{71} Sontag.1978. \textit{Illness as Metaphor}, 57
\textsuperscript{72} Ibid., 46
sees that the man in the picture on the campaign poster has a beard and is wearing trendy accessories such as oversized glasses, a plaid scarf and a snapback hat. The features of the observed are compared with the viewer’s preferred form of those features. He identifies that this style is characteristic of the ‘hipster’ group. As a result, the viewer begins to think of the other features that characterize hipsters, perhaps the elitist attitude typical to most who identify as a hipster. Based on the viewer’s intuitive, rather than empirical or reasoned, perception of the individual, the viewer places the viewed on a normative scale of behavior and appearance. The viewer then adopts a negative attitude of the man in the campaign poster. Though this example may have only a weak connection to the moral character of the pictured individual, the process of judging moral character is the same, according to LCA. In the “No One Deserves to Die” advertisement materials, the audience is told that they do not prefer the features they observe in the provided image. Therefore, the audience is told that the characteristic is different, reprehensible, and reveals undesirable behavior and moral weakness. When judging someone with lung cancer, the viewer’s analysis determines that the individual is less worthy than those who previously exercised more responsibility for their health. As a result, the final judgment is that individuals who smoked ‘asked for it’ (lung cancer), and therefore, deserve to die. LCA considers this conclusion inconsistent. The audience is judging the hipster based on his outer appearance alone. LCA is drawing the parallel that society also judges individuals with lung cancer based on insufficient information and inappropriately attaches a moral identity to the individual. In this way, LCA brings forth a relationship between disease, identity-making and responsibility.
The television advertisement tells the viewer outright that “lung cancer doesn’t discriminate; neither should you.” This is to say that lung cancer does not only affect a single type of person; society should not discriminate against individuals on the sole basis of diagnosis with lung cancer. LCA wants to make it clear that a person’s identity is constituted by more than a single behavior. Classification by a single behavior, as a ‘cat lover’ for example, may tell others some information about the individual; however, this behavior does not directly indicate moral character. The campaign aims to recast people with lung cancer as ‘patients’ rather than deviants. When analyzing Western philosophers’ arguments about what makes character, Ian Hacking states that “the choices you make, situated in the thicket [of outside influences], are what formed you and continue to form you.” Based on this idea, character is not a fixed entity. Therefore, the person as presented in a particular context, such as provided through the “No One Deserves to Die” campaign, does not indicate who he truly is, was or will be in the future.

Not only is discrimination as a result of a single fact about a person unacceptable, but asserting a punishment on that basis is morally unacceptable. The campaign moves beyond identifying the source of injustice stemming from society’s commonly held perceptions, to also proscribe society’s negative, ill-informed reactions. In this way, the campaign extends itself to directly confront the stigmatizers’ attitude toward the stigmatized. Not only does the campaign oppose identification of those with lung cancer as ‘deviant,’ this stage of the campaign is asserting that devaluing this group is outside the appropriate range of responses. In this way, the campaign’s major function is actually

defining appropriate social attitude for *stigmatizers* rather than boost the image of the stigmatized patient. LCA aims to transform the viewer’s attitude from negative into a tolerant attitude that rightly views the person with lung cancer as a patient in need of compassion and care. By shifting away from previous labels of ‘immoral and irresponsible,’ toward ‘patient’ the hope is that some of the negative connotation will fall away and alleviate the injustices LCA seeks to correct. To frame lung cancer in terms of a biological anomaly, rather than the consequence of a voluntary behavior, removes the moral responsibility for the disease.

Medicalizing lung cancer as a solution for reframing stigma is interesting. Stigma and medicalization offer different ways to view the same issues. Each frame carries expectations about the individual’s responsibilities and the space he should occupy. Traditionally, medicalization has been viewed in social theory as an inappropriate application of medical solutions to a social problem. However, the medical viewpoint is desired in order to recast lung cancer as a biological disease, rather than a moral failing. Lung Cancer Alliance implies that this is a case that should be considered from a medical perspective; lung cancer should exist in a medical space, that addresses the social problems associated with lung cancer. However, a medical framework does not remove all social aspects of the problem. Shifting the frame toward the medical view carries implications for the way the patient exercises his rights and what rights he has. The medicalization literature of the 1960s and 70s viewed the phenomenon as a measure to legitimate the medical profession at the expense of the individuals’ rights. Medicine establishes its own norms; the expectation that a patient comply with all reasonable treatments becomes the yardstick against which all patients are measured. Should he
fulfill this patient role, he can legitimately make claims on the medical community for care. If he does not fulfill his patient role, he is identified as non-compliant, and has a diminished ability to make claims on the medical community. Ultimately, medicalizing public attitude about lung cancer characterizes the individual with lung cancer as a patient and shifts responsibility back to the patient for managing his disease.

V. Dissociate the Disease from the Diseased

Goffman states, and Minow supports, the idea that social interaction is made uncomfortable when difference is presented in an unexpected way. Lung Cancer Alliance knows this and adopted this strategy. The “No One Deserves to Die” campaign has made society question their preconceived notions. It made us uncomfortable. It made us question what it means to have a disease that we are not allowed to ask for help in order to manage it.

The Lung Cancer Alliance case brings forth important features of understanding disease in the stigma framework. The non-profit organization proposes the concept of stigma as a given, a closed thing that exists. Whereas what they are really doing is asserting stigma as not only a possible a way of understanding the disease and response, but also the way that we actually understand and frame the problem of injustice and negative attitude about lung cancer. This kind of attitude about a disease is problematic because the patient’s health and identity suffer as a result. LCA’s hypothesis is that confronting and removing this negative attitude would allow patients to be more open about their disease, stimulating conversation and awareness. The “No One Deserves to Die” campaign calls this phenomenon ‘stigma’ and uses this framework as a way to bring
forth a relationship between disease, identity-making and responsibility. LCA asserts that the constructed identity is a key method causing injustice to lung cancer patients. This leads me to question how this relationship is made, given that Lung Cancer Alliance’s stigma narrative flattens out the relationship between disease, identity making and responsibility? Given this shift from stigmatization toward medicalization and the mission of destigmatizing lung cancer, my original hypothesis was that medicalization of a disease, or understanding the disease in objective medical terms, would necessarily entail elimination of stigma and normative judgments of the disease and the person living with the disease. It turns out the idea that medicalization equals destigmatization is an oversimplification of how social problems are understood and framed. And, how is the perspective of those issues shifted by medicalizing the problem of injustice toward lung cancer patients? LCA proposes that devaluation of those with lung cancer should be addressed by medicalizing the problem, so as to correct the marginalization that lung cancer patients currently experience. In the medical space, LCA seems to hypothesize that judgment of character is de-emphasized, potentially allowing lung cancer to be regarded as equal to any other cancer. In the medical framework, it is thought that public perception of lung cancer becomes objective. LCA posits that this shift will change the nature of the problem and promote awareness and increased research funding. In this way, lung cancer can overcome the injustices that have prevented it from garnering the support that other cancers have received.

Instead, these two frameworks emphasize the same things, but in different ways. Both frameworks describe a relationship between identity, responsibilities of society and a disease. Stigma and medical frameworks of disease each offer a method to explain
difference. Yet, the norm is encoded in both of those constructions of difference. The
norms lead to expectations of the patient. Each frame implies individual responsibility in
some manner. Each framework also provides a tool for exclusion and inclusion. By
categorizing the patient in each frame’s respective terms, the individual is identified in
terms of the space he should occupy. Additionally, each frame acts as a justification for
allocation of rights. In the frame LCA calls ‘stigma,’ lung cancer patients are excluded
based on their difference from other patients. These patients are not able to make claims
on society for more research dollars or better care. By medicalizing the disease and
shifting the frame, lung cancer patients take on an active responsibility for their disease.
It is his role, as a patient, to comply with reasonable medical treatment. This can be
considered a procedural responsibility; the patient simply has to follow through with the
prescribed treatments and interventions at the appropriate times. Should he do this
successfully, he has earned the label of patient. He is then able to make claims on the
medical community for further care and on larger society for funding to enhance research
benefitting his disease. With this possibility, responsibility is assessed both passively and
actively. These lower level negotiations by the patient, medical community and society
help draw out the larger picture. The relationship between disease, identity-making, and
responsibility as seen in these frames become ways to operationalize difference.
Difference becomes a tool for exclusion or inclusion which is a common feature of both
the stigma and medical frame. Each of these frames, however, assess difference in its
own manner. Because of this, the moral aspect of disease is understood differently in
each frame.
CHAPTER 4

THE STIGMA FRAMEWORK

I. Introduction

Lung Cancer Alliance’s “No One Deserves to Die” advertising campaign reveals a relationship between disease, identity-making and responsibility. Analysis of this case serves as a tool to examine this relationship as it relates to the underappreciated moral aspects of disease. Given the analysis of the case, and Lung Cancer Alliance’s focus on the stigma and medical frames, it is useful to examine these frames. I will explore these frames in order to understand the aspects that are collapsed in the “No One Deserves to Die” campaign in the following two chapters. A fuller understanding of what these frames actually signify will provide a clear explanation of how and where these relationships are made. In this chapter, I ask, given that Lung Cancer Alliance’s stigma narrative flattens out the relationship between disease, identity making and responsibility, how is this relationship made? By this I mean, what foundational interactions generate the relationship between disease, identity, and responsibility, which is highlighted by Lung Cancer Alliance? The theoretical analysis in order to answer the question will enliven the intricacies of this relationship LCA points to in its campaign. This chapter examines the concept and framework of stigma as developed in sociological literature in order to understand the connections between disease, identity-making actions, and responsibility. LCA suggests that stigma is a given. LCA discusses the problem of stigma as a problem of public attitude. But what are the collectively held meanings of stigma that LCA is dipping into in order to get stigma to connect disease, identity-making and responsibility in the campaign? Treating negative public attitude as a given ignores the
work that goes into creation of the attitude. Review of sociological literature highlights concrete social behaviors that contribute to the problematic public attitude LCA directly confronts in the “No One Deserves to Die” campaign. By calling it stigma, LCA is referring to a set of problematic social relationships. The organization’s exploitation of stigma tells us something about the common-sense meaning of stigma vis-à-vis disease. I would like to use this concept as a tool for analysis to pull these relationships apart.

LCA tells the story of lung cancer as a narrative of stigma. LCA suggests the problem of public attitude, which they frame as stigma, can be remedied by shifting toward a medical understanding of lung cancer. Therefore, the same question is asked in relation to the medical frame in the following chapter. Another question will also be asked in the following chapter: how is the perspective of the problem of injustice toward lung cancer patients shifted by medicalizing the relationship between identity-making, disease, and responsibility? The theoretical analysis in these two chapters will be used as tools in order to provide a clear explanation of my overarching line of inquiry into the moral aspects of disease.

In *Illness as Metaphor*, Susan Sontag focuses on the social meanings TB and cancer carry even after historical basis for those meanings fell away. The lingering meanings leave society with identity markers, but little understanding of their origin. When it is unclear why a certain group is blamed for a disease, explanation degenerates to a pre-reflective “that’s just how it is.” Because stigma is a discrepancy between expectation and reality, as Goffman describes, the application of the concept is unique in each situation. Health conditions are tractable surfaces to attach stigma because, health and disease is normalized by medical knowledge. The stigma carries the meaning that the
stigmatized does not conform to the normal health regimen. Those with a certain health issue are different enough from others in his social circle that it feels justified to the group to judge that the individual’s deviance from their norm is unacceptable. In his discussion of disability and the Civil Rights Movement, Joseph P. Shapiro states that “fear, disabled people understand, is the strongest feeling they elicit from nondisabled people.” He continues on to describe that the stigmatized attribute reminds the viewer or the other of the uncertainty of his relatively ‘healthy’ condition. In this way, fear fuels stigma. People tend to expect to be healthy indefinitely, however, the reality is that our healthy state is transient at best. The transient quality is undesired and if we fight against it, we can extend our health as much as possible. Thus, those who succumb to ill-health early can be seen as someone who did not fulfill his duty to his health. Not only is this outside the social expectation that the citizens maintain their health, but it calls into question a ‘normal’ individual’s responsibility toward health. As proof that regular exercise and healthy diet are good for an individual, but not necessary for survival, it calls others’ behavior into question.

Charles Rosenberg describes several diseases for which meaning is ascribed based on the disease history and the patient experience beyond the literal, clinical definition of the disease. The disease frame is constituted by the disease history and the lived experience, which society responds to based on a disease-specific set of assumptions. These boundaries for the disease frame are essential for understanding the identity of the individual as a patient. His analysis summarizes the importance of place and time in framing disease and postulates that the literal biological nature of the disease also

contributes to the frame that results from intellectual work regarding a disease.\textsuperscript{75}

According to Rosenberg, the diagnosis is an important step that sets up the initial frame of the disease. A stigma framework of disease emphasizes identity-making and responsibility as key components contributing to the moral aspects of the disease. The stigma framework takes on slightly different characteristics in relation to specific disease as a result of unique disease history. In the same vein, the appropriate intervention on a stigma framework is unique to the disease being framed.

Lung Cancer Alliance has operationalized stigma in such a way that describes the relationship between lung cancer, identity and responsibility. LCA’s campaign collapses this relationship, which they frame as stigma, in a way that glosses over the social actions that create a stigmatized understanding of disease. The campaign ignores how public attitude about lung cancer was made. Society’s actions (comparing types, assessing difference, and allocating rights on that basis) classify its understanding of disease within the definition of stigma. The definition of stigma has evolved over time. The changing definition also reveals a historical shift from stigma as a concept in social theory to stigma widely used as a framework for understanding social interaction with disease.

II. Definition and Ambiguity: Features of a Stigma Framework

Erving Goffman’s 1963 book, \textit{Stigma: Notes on the Management of Spoiled Identity}, provides a thoughtful discussion of what stigma means, in terms of definition, individual management and group negotiation of the concept. Erving Goffman is one of the most frequently cited sociology scholars who dealt explicitly with the concept of stigma.

\footnote{Rosenberg, Charles E. 1989. “Disease in History: Frames and Framers,” 14}
stigma. His characterization of stigma has made a large contribution to the field of sociology generally, and understanding the social experience of disease specifically. Goffman describes stigma most succinctly in the preface of *Stigma* when he describes it as “the situation of the individual who is disqualified from full social acceptance.” He also defines stigma alternatively as “an attribute that is deeply discrediting,” an “undesired differentness from what we had anticipated.” It is because of this difference, this deviance from the norm, that the stigmatized individual is “reduced in our minds from a whole and usual person, to a tainted, discounted one.”

As we move through other definitions, the concept is shifted away from Goffman’s original formulation of stigma. Gerhard Falk states that stigma “occur[s] whenever and wherever some people find behavior or characteristics of other people offensive and/or reprehensible.” Anne Hendershott defines stigma as “a powerful negative label that fundamentally changes a person’s social identity and begins to operate as a master status.” Goffman would disagree with this definition; he notes that the attribute itself is amoral, rather the social response to the attribute is the force that attaches a moral implication to the attribute. Ian Hacking states that a realist would argue “the disease itself is an entity in its own right, independently of how we classify it.” Similarly, the realist may argue that behavior is carried out regardless of what it is called or the moral judgments made about that behavior. Whereas the nominalist would argue

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77 Ibid., 3; 5
78 Ibid., 3
identity of things and people is entirely constructed and, thus, is not based on the true nature of that entity. Hacking argues for dynamic nominalism, in which both of these actions occur simultaneously. If “the category and the people in it emerge hand in hand,” then the label and the nature of the attribute both contribute to the resulting identity. Rosenberg explains this connection with his statement that, “in our culture, a disease does not exist as a social phenomenon until we agree that it does.” Therefore, labeling is both a driver of social reality, and a result. Inconsistencies such as these in the definition of stigma as a concept is repeated functionally when stigma is deployed as a framework for understanding a disease without first clarifying its relationship between the disease and the moral identity it is said to describe. Though a general consensus about the definition of stigma has been reached, there is no single, all-encompassing definition of stigma.

As one progresses through the definitions of stigma, a shift from concept as a neutral mark to a normative entity of underlying character becomes visible. Goffman postulated a definition for the concept of stigma in itself in 1963. In his definitions, stigma is a “situation” or “difference” which are objects modified by adjectives provided through social response. He notes that the attribute itself, causing stigma, is amoral; rather the social response to the attribute is the force that attaches or removes value from the individual carrying that attribute. He states this reflects the Greek definition that indicates the individual is a physically “blemished person.” In 1978, Susan Sontag described that stigma is applied to a disease by attaching the disease with metaphors

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82 Ibid., 104-106
which connect the appearance of the disease with the character of the diseased. In this way, the underlying character of the individual is emphasized over the physical attribute associated with stigma as the definition moves away from the Greek formulation of identity. In 1988, Sontag cites Goffman’s “spoiled identity” definition of stigma in *AIDS and its Metaphors*, and declares society has moved away from this formulation of stigma as applied to cancer. Cancer has become less feared, and therefore, less burdened by stigma. She states “cancer is treated with less secrecy” in recent medical practice. In addition, AIDS (Acquired Immunodeficiency Syndrome) is the new disease “identified with evil, and attaches blame to its ‘victims;’” there can only be one such disease after all. Given Sontag’s explanation, lung cancer should not be understood in terms of stigma. However, fear is not the only social aspect of identity-making that can be understood in these terms. Definitions proposed in the 2000s follow Sontag’s trend toward including social aspects of the concept. Falk’s definition in his 2001 book emphasizes the social response to ‘the mark,’ which is colored in negative language. Hendershott’s 2002 definition explicitly states that stigma is a “negative label” that overtakes one’s identity such that he is the label, and nothing beyond it. Furthermore, normative response to a specific personal feature is not universal; it is subject to time, place, social context. Therefore, the negative label Hendershott describes does not always apply. I include her definition because a) it explicitly includes the concept of identity, and b) it seems to capture the perspective of the individual living with stigma.

86 Sontag, Susan. 1978. *Illness as Metaphor.*
88 Ibid.
The intellectual definitions are structural, whereas her iteration speaks to the lived experience. Link and Phelan state that each discipline may offer a diverse understanding of stigma. Sociological literature provides a better understanding of the components that Link and Phelan describe in their definition of stigma: the co-occurrence of its components—labeling, stereotyping, separation, status loss, and discrimination.” I find the separation of these aspects to be somewhat artificial, and will discuss them in terms of a combination of Martha Minow’s “difference dilemma” and Goffman’s discussion of professional presentation of stigma and the concurrent implications for responsibility. The progression through definitions of stigma begin to reflect how public attitude about disease is formed. The following discussion will continue to break apart the discrete social actions these theorists point to which form the relationship between disease, identity-making and responsibility that the “No One Deserves to Die” campaign brings forward.

III. Concept to Framework

As the definition of stigma shifts toward a normative assessment, a parallel shift from concept to framework also occurs. By taking normative actions based on the definition of stigma, this concept is enacted as a way of understanding and responding to a disease. Furthermore, the connotations the definition has accumulated (the negative connotations in this case) influence the way in which the concept is applied. The negativity that often accompanies stigma signifies a major public assumption that the

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person who is stigmatized is bad and deserving of such negativity. Encoding the very
definition in this way pigeonholes stigma’s use, providing a limited understanding of
those to whom it is applied. Lung cancer, in this case, is therefore understood and
responded to in a specific way within this framework of stigma. By asking the question at
the beginning of this chapter in a slightly different way, what does Lung Cancer
Alliance’s use of stigma tell us about our cultural common sense about disease frames?,
the literature reviewed here and above show that a normative judgment about the
individual has become our common sense understanding of disease frames. This limited
progression from a widely cited definition of a concept toward a normative framework is
only one side of the story; it is likely that the definition of the concept/framework shifted
in response to common application of the concept. An in-depth genealogy that examines
the emergence and interdisciplinary understanding of the concept/framework would be a
rich area of future research, though is beyond the scope of this project. Such an
understanding of how stigma became a tool to understand social interaction, especially in
relation to one’s disease status, would have diverse applications across history of
medicine, clinical practice and public health. But for my purposes it is sufficient to note
that, Lung Cancer Alliance’s use of stigma as a framework is legitimated by the very
evolution of the definition and practical application of the concept of stigma to disease.

IV. Comparing and Judging Difference

As stigma has become connected with specific assumptions, and in turn become a
normative understanding of disease, it becomes clear that norms are embedded in public
attitude. The “No One Deserves to Die” campaign glosses over how this public attitude is
made. When a group like LCA states stigma exists, with little theorizing about the precise social interactions they are characterizing, the creation of stigma is a given. LCA does not explain how a stigmatizing attitude comes to pass. In their employment of the term, it just is. As I have explained in the previous chapter, LCA problematizes this attitude in terms of stigma. LCA tells the audience that it holds a negative public attitude about lung cancer. LCA does not explain how such a public attitude came to be. The group is emphasizing the effects of understanding a disease in terms of stigma. The LCA case shows that, for the concept of stigma to apply, and for it to frame social relations in the terms outlined above—from comparison and difference assessment to attaching a moral valence and allocating rights and responsibility on that basis—its framing effects need not be explicit or recognized. By asserting that stigma exists, and eschewing the work to convince the audience that it is so, LCA positions the audience as stigmatizer. LCA thereby opens the door for stigma to be a mode of characterizing the social position of the diseased. Stigma and the process it refers to, then, plays a large role in identity-making.

The literature shows that one does not inherently fit a norm, as the common sense nature of the campaign suggests. Martha Minow discusses that discrete social actions must occur to classify an individual as normal or other. In order to determine if one fits the norm, he must be compared to that norm. When some feature of his identity goes against the expectation, he is judged to be different. As a result, space is made for new identities. This process is not merely a naming process reflective of a passive truth, but rather a “dynamic nominalism,” says Ian Hacking, in which “the category and the people
in it emerged hand in hand.” Not only does it frame one’s identity, but it creates new possible identities, according to Ian Hacking. Characterizing labeling this way makes Charles Rosenberg’s argument that “every aspect of an individual’s social identity is constructed” more robust.

As a particularly significant point, Martha Minow states that difference becomes problematic when it functions as a set of “unstated assumptions.” Difference becomes a feature where rights are assessed inappropriately when difference is assumed: to be intrinsic; in relation to a norm that does not need to be stated; able to be assessed without influence of perspective; without input from other perspectives; and, based on a status-quo that is natural and good. In her formulation, a comparison leads toward a diminished identity that can be marginalized when comparisons between types of people are made with no acknowledgment of the bias or perspective of the observer. As a result, the difference “pigeonhol[es] people in sharply distinguished categories based on selected facts and features.” In this way, the difference is made to seem a true feature of their identity, whereas, it is really a reflection of the perspective of the observer.

When difference is the background, a normative judgment of the individual is then made. From the lung cancer example, it is clear that the lung cancer patient is assumed to have a role in causation of his disease. In this way he is different from other

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92 Ibid., 106-108
96 Ibid., 53
cancer patients. Thus, judgment identifies him as a risk-taker, unworthy of the benefits other cancers enjoy. The “characteristics that are deemed socially significant” are the interesting sites where difference is framed as stigma.” Characteristics become socially significant when a comparison yields difference that departs from an acceptable spectrum.

These differences highlighted in the newly created identity can be explained by employing normative claims about the individual as the identity is recognized and negotiated by society. Goffman might describe the addition of normative claims about a neutral label in terms of stereotyping. A stereotype is understood as an identity commonly given to a certain group of people with the assumption that it accurately describes those people; often with the intention of applying an analysis of the person rather than simply labeling that person. I find the concept of a stereotype problematic in practice as stereotypes tend to linger beyond their usefulness. Indeed, a stereotype is a type of identity that captures a picture of society at a specific moment. It infuses a particular value held by society at a certain time into a classification of a person. Because a stereotype tends to be a static entity that is broadly applied, it does not seem to match Hacking’s description of the dynamic features of framing or identity making. Relying on stereotype seems to limit the possible categories an individual can occupy. Link and Phelan hint at this when describing a stereotype as a way to “make shorthand decisions” about other people so as to avoid spending too much time or reasoning power on trying to categorize others. The Lung Cancer Alliance case demonstrates that flattening

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97 Link and Phelan. 2001. “Conceptualizing Stigma,” 368
98 Link and Phelan. 2001. “Conceptualizing Stigma,” 369
differences in this manner causes more harm to the patient than benefit provided to society. In the case provided, the norm is encoded in the construction of difference. Martha Minow explains that this occurs because “reasoning processes tend to treat categories as clear, bounded, and sharp edged… instead of considering the entire individual, we often select one characteristic as representative of the whole.” The identity resulting from the perceived difference goes beyond a flat perception of a type of person, and becomes an object to be categorized as ‘normal’ or ‘other.’ By creating a category for a person that is not whole, it more clearly defines those that can be considered whole.

Separation on the basis of difference is justified in the social consciousness based on deviance from the norm, the third defining piece of stigma. Anne Hendershott explains the body of classical deviance literature shows agreement that deviance is “the social pressure to conform and be normal.” Her analysis of Erving Goffman concludes that he characterizes deviance as a “consequence of acquiring a stigma;” an identity that is applied after the individual is discredited. On the surface, this conflicts with Link and Phelan’s definition of stigma, which implies that deviance, in the form of separating types of people, contributes to the resulting stigma framework applied to a group or individual. Based on their definition, a stigmatized understanding of the disease results from separation by defining two different types of people. The act of defining a deviant includes defining who does not fit within the frame designated “normal;” this could also be described as the act of conceptually creating categories in which to place people.

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101 Ibid., 32
new category of people is then discredited on the basis that they are the type of people to occupy that category. Link and Phelan’s definition does not specify whether defining people or defining categories contributes to the stigma frame. It may be impossible to make that distinction and serves as an example of Hacking’s argument that the label and the category simultaneously contribute to the stigma framework.

Making such a distinction between a whole and compromised identity leads to new responsibilities for the sick individual who is not considered whole. Sontag suggests that he is burdened with “the ultimate responsibility both for falling ill and for getting well.”¹⁰² The stigma framework does not provide a clear idea of how the patient should take responsibility for getting well. Goffman describes how the individual can take responsibility for falling ill though. He states that the stigmatized appropriately fulfills his role when he walks a fine line between concealing his stigmatizing feature in public and having reached a level of personal acceptance of that feature such that, when it is revealed in public, it is easy for ‘normals’ to offer acceptance.¹⁰³ Goffman calls this social expectation “good adjustment” and the one that carries this out the “gentleman deviant.” Good adjustment is demonstration that the sick individual is holding himself responsible for falling ill by bearing his stigma honorably, without letting his difference embarrass those around him. Meanwhile, the “gentleman deviant” himself, one who is a “nice person like ourselves in spite of the reputation of [his] kind” is never expected to leave this liminal space, but rather toe this line until his stigma disappears (if ever). To

¹⁰² Sontag, Susan. 1978. *Illness as Metaphor*, 57
reject this and attempt to become fully “normified”\textsuperscript{104} would be indicative that the individual is not accepting responsibility for falling ill. He is being dishonest with himself and to society about his shortcoming.

Conversely, Lung Cancer Alliance emphasizes society’s responsibility. LCA skips over the theoretical argument that an individual with lung cancer should take responsibility for his disease. In doing so, LCA partially absolves lung cancer patients’ individual responsibility for the disease and places responsibility for the negative disease identity attributed to lung cancer with larger society. Because society’s perceptions of this group are unfounded, society is at fault for casting lung cancer patients in a negative moral light. Society is responsible for diminishing lung cancer patients’ rights, or ability to make claims on society, to representation in medical research and care. By representing lung cancer patients as victims of societal misperception, LCA is “making consistent sense out of [the] situation” and professionally presenting individuals with lung cancer in Goffman’s terms.\textsuperscript{105} LCA acts in an authoritative capacity to officially manage the identity of individuals with lung cancer in their place. LCA suggests lung cancer patients should be understood as patients. The expectation is applied in two ways. First, it applies to larger society, asking that it change its attitudes about lung cancer patients. Second, in order to for lung cancer patients to be understood out of the context of a moral valence, they become responsible for assuming a new role. In some ways, LCA’s organization of lung cancer patients as a group absolves the group of the moral

\textsuperscript{104} Goffman states, “Normalization is to be distinguished from ‘normification,’ namely, the effort on the part of a stigmatized individual to present himself as an ordinary person, although not necessarily making a secret of his failing.” Goffman, Erving. 1963. \textit{Stigma: Notes on the Management of Spoiled Identity}, 30-31

responsibility that the framework of stigma is build upon. Yet, LCA’s suggestion that lung cancer patients should be considered patients rather than moral deviants indicates that patients are responsible for their disease in a new way. The argument that CT screening and high-level medical care be available to all indicates that the patient (or potential patient who is ‘at risk’) should accept a medical understanding of the disease.

V. Rights and Difference

LCA’s minimalist campaign glosses over all theoretical contributions to the concept of stigma. By glossing over the identity-making interaction that include comparison, attributing difference, and making normative judgments, LCA allows the origins of society’s problematic, negative attitudes toward a group like lung cancer patients to go unnoticed. Letting the complexities of this process go unstated, LCA’s invocation of stigma implies society has undergone this identity-making process. Yet, the process itself goes unexamined. Take for example the assertion that an individual, or group of people, “deserve to die.” This statement is based on an interpretation that the stigmatized individual committed some reprehensible behavior for which he should bear the consequences. This example implies the individual is resigned to a less worthy life, one that should not continue. If it is the case that the distinction between a life that should continue, and a life that should not continue comes before the specific discrediting feature or behavior, then the stigmatized group’s identity is based on society’s devaluation of that feature/behavior. Specifically, the value that nonconformity, especially in the form of risk taking behavior, deserves punishment. Those who enact the discrediting behavior are then moved into the stigmatized category and become worthy of
punishment. They are not only subject to punishment, but a diminished claim for life. Conversely, a feature or behavior that disqualifies members of a group from claiming full personhood could contradict society’s values and constitute the boundaries of a new available category in which to place people. If these two situations happen simultaneously separation and label making contribute to an identity that has a diminished right to make claims than the rest of society; this group of people has lost their right of life. Based on the interaction of separation and label-making, the resulting stigma effectively denies rights to groups and individuals. Given that it is not uncommon to hear that someone deserves to die, especially in relation to a disease for which there is a known health risk, we can conclude that separation based on this attitude is accepted in society to some extent. Even when the group is made up of “gentleman deviants” who demonstrate “good adjustment,” the social response may be less dichotomous, yet stigma remains. The group is still labeled as those who exhibit behavior against the norm.

The organization implies that society has undergone this process of identity-making. Going unexamined, the theoretical process is glossed over. However, these theoretical concepts build an identity which becomes the basis for which individuals are ascribed certain responsibilities. This connection is simplified to a fault in the Lung Cancer Alliance campaign, but it is an important driver of public attitude. Comparison, assessment of difference and normative judgment are important aspects of social interaction that significantly shape the relationship between disease, identity-making and responsibility. Lung Cancer Alliance is referring to these social actions when it says ‘stigma.’ The problematic public attitude about lung cancer can be traced back to these social actions. It can be traced even further as a negative moral judgment became
embedded in the definition itself. Framing the disease in terms of stigma, when that means society’s (often unconscious) reasoning about those individuals is colored by a moral calculus, again encodes a general attitude about the group. Because the encoded attitude is negative, marginalization follows the normal response to an unworthy group. Traditional sociological text suggests the individual is responsible for accepting and changing his disease. The stigma framework does not provide a clear way for the individual to manage his disease identity moving forward. Lung Cancer Alliance absolves the individual with lung cancer of any responsibility for his current situation. This position follows the logic that “as long as disease is something that takes possession of people, something they ‘catch’ or ‘get,’ the victims of these natural processes can be exempted from responsibility for their condition.”

Instead, LCA places blame on society itself for stigmatizing the patient. Lung Cancer Alliance offers the medical framework as a solution that purportedly reaches for moral neutrality, and offers a clear method for the individual to take responsibility for his disease moving forward.

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CHAPTER 5
MEDICALIZATION

“Health has ceased to be a native endowment each human being is presumed to possess until proven ill, and has become an ever receding goal to which one is entitled by virtue of social justice”\textsuperscript{107}

- Ivan Illich, \textit{Medical Nemesis: The Expropriation of Health}

I. Introduction

Lung Cancer Alliance proposes that the public attitude and understanding of lung cancer should be medicalized. The injustices that LCA emphasize, especially low federal research funding and high mortality rate, stem from a lack of attention from the medical community. LCA seem to indicate that shifting public perception of the disease to be framed in terms of a medical problem would garner more funding and create structural support for the lung cancer patient. The call for a shift itself implies both a failure (by society) and a remedy. The proposed remedy draws on the medical frame to reorganize society’s problematic attitude. Therefore, the relationships that help build the public perception are medicalized. The medical framework is a solution for LCA that would diminish the moral aspects of lung cancer and ease the injustice individuals with lung cancer are currently experiencing. LCA’s picture of what it means to destigmatize lung cancer is revealed by appealing to the medical frame. How is the perspective of the problem of injustice toward lung cancer patients shifted by medicalizing the relationship

\textsuperscript{107} Illich, Ivan. 1976. \textit{Medical Nemesis: The Expropriation of Health}, 122
between identity-making, disease, and responsibility? After a review of the definitions of medicalization from the sociological literature, and a brief overview of the history, I will use LCA’s call for medicalization as a tool to understand the relationship between disease, identity-making, and responsibility in the medical frame. The same reasoning that contributes to this relationship in the stigma framework applies here, with some alterations. Rather than beginning with a comparison intended to categorize the person, the individual is initially placed in the patient category until he proves himself unworthy of that title. Based on assessment of his active responsibility toward his care, he is either allowed to remain a patient, or is considered non-compliant and his patient identity is ‘marked’ or diminished. As such, the patient’s identity and responsibility for his disease are intertwined in a more complex fashion. This complexity is ignored in LCA’s recommendation that public attitude is shifted to a medical understanding of lung cancer. Thus, I argue that the moral aspects of disease do not seem to be removed as LCA suggests.

II. Definition

The definition of medicalization has changed since the term was first applied in the mid-1900s. It is generally accepted that medicalization, in its most bare definition, means ‘to make medical,’ indicating a social problem is being considered with a medical viewpoint. However, an interesting discussion has arisen out of the more complete, working definition. As meaning has been ascribed to the term, its definition has changed and reconstructed in a few different ways. Peter Conrad, an American sociologist, states:
“Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to treat it. This is a sociocultural process that may or may not involve the medical profession, lead to medical control or medical treatment, or be the result of intentional expansion by the medical profession.”

A similar definition provided by Peter Whelih et al. in a letter to the editor of the German/English bilingual journal Deutsches Ärzteblatt International highlights that the ‘problem’ is a social phenomenon. They state “Medicalization is a process by which a social phenomenon that to date was not perceived as medically relevant now becomes defined by medical terms and/or treated with medical means.” This definition provides a clearer picture of what Peter Conrad spends a great deal of effort to explain in his article in the Annual Review of Sociology. The emphasis of these definitions is the process of applying medical knowledge to a non-medical problem. Conrad’s 1992 definition quoted above emphasizes the conceptualization of a social problem as a medical problem. Whereas, in 1975, Conrad’s definition includes to an equal degree the idea that medicalization means a social problem is framed as a medical problem, and idea that this frame appropriately places the problem within one of the medical field’s many roles. The 1975 formulation of the definition stated medicalization meant “defining behavior as a medical problem or illness and mandating or licensing the medical profession to provide some sort of treatment for it.”

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management of the problem. This is referred to as the “jurisdictional aspect” by Joseph E. Davis. Drew Halfmann agrees with Davis, both contending that the ‘jurisdictional aspect,’ which was later removed from the definition, was an important feature, necessary for understanding the concept.

The criticisms regarding the redefinition of this phenomenon posed by Halfmann and Joseph E. Davis center on the idea that medicalization needs to be understood in its full medical context; by changing the definition, the true meaning of the process is lost. Davis contends that the inclusion of the jurisdictional aspect in the definition provides a sense of the boundary between legitimate and “illegitimate extensions” of power by the professional medical field. The removal of the implied boundary removes the problem medicalization poses, which is the problem of inappropriate application of medicine and the medical framework to everyday life. Davis further criticism lies with the loss of control over the use of the medical frame. The new formulation of the definition becomes open to “any group or individual’s use of such terms/frameworks,” which he finds problematic because “outside the sphere of medicine, we have no way to determine what constitutes a ‘medical’ term or framework.”111 In other words, the ability to frame a problem as a medical one provides a new way to characterize problems that may arise and, therefore, a new way to categorize the people those problems affect. While criticism that removing the jurisdiction component from the definition takes away from the concept of medicalization, understanding of the ways in which other types of groups use medicalization would provide important cultural knowledge. As I will discuss later, the way in which a ‘medical term or framework’ is used highlights influential sources of

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knowledge. Those sources contribute to a patient’s understanding of his/her illness the resulting shift in identification after diagnosis. Explicating the factors that shape the social context is an important task since “what qualifies as biological disease or biomedical evidence is often socially negotioated and interpreted.”\textsuperscript{112}

Though Davis and Halfmann have a strong basis upon which to reject the newer definition of medicalization, I will use the definitions that emphasize adopting a medical frame to understand a social problem in this discussion as I try to understand the nature of the social forces surrounding medicalization. However, I will not discount the earlier definition; the evolution of the definition is important to provide a complete picture of the concept. The spirit of the 1975 definition is in line with the criticism of medicalization popular during the time period. Robert A. Nye points out that skepticism of the “medical model” at that time captured a tension between patient’s higher expectations and more sophisticated demands, and the profession’s desire for control.\textsuperscript{113} As we move forward into more recent history, other contributing factors come to light.

III. Levels of Medicalization

There are several proposed systems for understanding the spectrum of medicalization. Drew Halfmann discusses the typology of medicalization proposed by Conrad and Scheider and proposes his own typology. Central to his proposal is the idea that the level of medicalization increases or decreases in response to social and scientific


variables. This is significant because scholarly literature often treats medicalization as a dichotomy; that it either does or does not exist.\textsuperscript{114} The typology Halfmann proposes includes three dimensions of medicalization: Discourses, Practices and Identities. He uses these dimensions as a way to structures his discussion of medicalization. Though this method has limitations, he states “the point is not to stuff processes and phenomena into boxes but to offer a sensitizing tool for identifying and analyzing medicalization.”\textsuperscript{115} With this in mind, I will employ this tool in order to help analyze the medical frame’s influence on identity making.

Discourse includes “sign, symptom, syndrome, disorder, disease, illness, pathogenesis, pathology, contagion and ‘normal function,’” or other biomedical language, vocabulary or definitions as part of the discussion regarding the topic at hand.\textsuperscript{116} Halfmann states “medicalization increases when [these features] become more prevalent in discourses about social problems” and conversely decreases when such features of a discussion becomes uncommon.\textsuperscript{117} This level includes contributions from medical journals and universities, legislation or other government, corporation or non-profit groups. These sectors are also contributing to the knowledge of the social problem simultaneously. The process and resulting knowledge of the problem has a strong influence on identity making since the new problem provides a new way to categorize

\begin{flushleft}\textsuperscript{114} Halfmann, Drew. 2011. “Recognizing Medicalization and Demedicalization: Discourses, Practices and Identities,” 189\end{flushleft}

\begin{flushleft}\textsuperscript{115} Ibid., 190 \end{flushleft}

\begin{flushleft}\textsuperscript{116} Ibid., 190-191 \end{flushleft}

\begin{flushleft}\textsuperscript{117} Ibid. \end{flushleft}
people. Furthermore, “without medicalization in a definitional sense, medical social control loses its legitimacy and is more difficult to accomplish.”

Practices, the second dimension, are the actions such as “measurement, normalization, surveillance, risk assessment, medical insurance coverage, examination, lab tests,” etc. which may be considered appropriate responses to a problem. Action within this dimension is the result of negotiations among laboratory science, clinical science, and general acceptance that a problem falls within the medical context. This influences the medical interventions he may offer the patient. As a medical practice is normalized, its availability entices a patient to request it from his physician.

The last type of factor influencing the medicalization story is the actor that addresses the problem, which could be any combination of “physicians, biomedical researchers, hospitals, insurance companies, drug and device makers, medical schools and professional associations, ‘clients’, and practitioners like midwives who are considered “less biomedical.” The identity of these actors is meaningful as they assume responsibility for addressing the problem. This is especially important as social problems become medicalized because the “biomedical” identity of the medical doctor reinforces medicalization of a social problem more so than, say, a homeopathic physician. Furthermore, the patient may also construct a “biomedical” self-identity around their diagnosis; as the ability to become this type of person emerges, the category

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120 Ibid., 191-192. For an extended example of how this typology may be applied, see pgs 192-196 and Table 2 on pg 194.
also becomes a possible way to organize people. In this way, a group identity can arise based on a biomedical classification.

IV. History and Discourses

“Reality does not just exist out there in the world waiting to be discovered, but rather is created by individuals who act in and toward their world.”\textsuperscript{121} Thus, medicalization was not deployed and set on a pre-determined track to reach some end point. Rather, medicalization began based on the interaction of several social influences and took hold as those social influences created a tenable landscape for the phenomenon.

According to Davis, the concept of medicalization was being discussed in the 1950s in relation to mental health by psychiatrists as they began defining relevant social issues with moral underpinnings in medical language.\textsuperscript{122} Though medicalization of social issues was occurring as far back as the sixteenth century, the situation Davis alludes to is based on different factors.\textsuperscript{123} John Burnham summarizes several factors that helped resurrect the phenomenon in the 1950s. Among them, consumerism and the open marketplace seem to have created a hospitable environment in which pharmaceutical tranquilizers were advertised extensively and prescribed based on patient request, rather than physician or psychiatrist suggestion.\textsuperscript{124} Peter Conrad, Frank Furedi and Frederic W. Hafferty identify medicalization discussion occurring in the 1960s, 10 years later than

Davis and Burnham describe. Further research into this discrepancy may identify an additional wave of medicalization.

This early application of biomedicine to moral problems is the basis for early rejection of medicalization as inappropriate application of medical knowledge to a problem beyond the professional biomedical scope. Davis cites Barbara Wootton’s distrust in the physician’s authority on moral issues and states “‘this victory of medicine over morals’ is improper in her view because the concepts of mental health and mental illness are not value-neutral, but disguise moral judgments.”¹²⁵ Neither this questionable basis for moral judgment, nor framing a social issue as a medical one have fallen by the wayside.

In “The End of Professional Dominance,” Furedi states that medicalization began based on the medical authority making achieved by professionalizing the medical field. This was largely achieved by implementing more rigorous training and higher standards for physicians, beginning with the Flexner Report. Published in 1910, the report surveyed the existing standards for medical education and signifies an important moment in medical history.¹²⁶ As a result of Flexner’s proposed changes like closing inadequate medical schools and improving the curriculum, medical education became more reputable. The Flexner Report did not just make the curriculum more rigorous, but also called for it to be based more strongly in the hard sciences. Deferring to scientific data provided the M.D. with further legitimacy. As a result, a division arose between a

‘qualified physician’ and another type of practitioner or healer, lending more credibility to the physician with a prestigious medical education.

The scientific basis of medicine has been questioned by many, including theorists, ethicists and doctors themselves. Leonard Tushnet, a physician, calls the entire practice of medicine into question in his book *The Medicine Men*. His criticism of every feature of medicine from the language and vocabulary used, the instruments and methods applied and the treatments prescribed, leads him to the conclusion that, despite the increased ‘scientific’ basis of medicine as a result of professionalizing the field, the mysticism of medical practice has not been removed. Rather, the lack of scientific understanding on the part of the physician and the patient has been replaced by a lack of understanding of the jargon and medical reasoning. A scientific basis of the medical profession makes the practice no more clear to the patient than that of the natural healer’s practice.

The question of true legitimacy of medical authority is valid, but it is beyond the scope of this study to situate the rise of medicalization. Early research into this topic commonly ended at the idea that medicalization is a result of medical professionalization. However, the sociological and anthropological lens has provided a new perspective on a seemingly straightforward medicalization narrative which is typically characterized as a result of professional legitimacy and scientific medicine. Attention to the interaction of social and environmental influences on health enrich the story. Furthermore, Frederic Hafferty makes the case “that today’s physicians occupy a more subordinate role than previously and that medicalization of today is dominated more by commercial interests
and market (rather than professional claims-makers).”

Thus, physicians and the medical profession are not the only driving force behind the medicalization phenomenon. It becomes a story of social negotiation of medicine’s role in identity-making.

The social factors promoting or detracting from medicalization are lost when it is simply discussed in terms of the paternalism of the physician. The medical community’s role in identity-making becomes more interesting when considering that a functional aspect of the medical experience, such as diagnosis or routine treatments, carry implications for the patient outside of the clinic. Epidemiological studies showing risk associated with behaviors become justification for placing responsibility with the patient for any negative health effects after the behavior is committed. Diagnosis, especially of a stigmatized disease with moral connotations, becomes a commentary on the individual’s character. Routine treatments, such as chemotherapy, are based on practical, biological reasoning, and yet structure an individual’s life in an external fashion. The patient is compelled to adopt a new structure to his life such that the health component takes precedence over other life activities. If he does not yield to this routine, he runs further risk of deviance, in the form of being identified as a ‘non-compliant’ patient, and further decline in health leading to ever more certain death. The significance of separating the disease from the morally causative behavior cannot be fully answered by rejecting a subjective interpretation of disease and appealing to a scientific viewpoint. Though the literature does not support the simple statement that medicalization = destigmatization, it is important to remember that LCA’s picture of destigmatization is stated as such. The organization looks to several injustices that they say could be remedied by more medical

and biomedical research attention. Should inquiry stop here, it would shortchange a full consideration of LCA’s solution.

V. Deviance and Responsibility in the Medical Frame

The moral aspect of the stigma framework is more straightforward than the moral aspect of the medical framework. Each framework contributes to a moral aspect of disease that is underappreciated. As discussed in the previous chapter, norms and social reasoning processes allow a disease to be understood in terms of stigma. These features of the stigma framework are hidden in Lung Cancer Alliance’s campaign. LCA also collapses what it means for the individual to enter the medical framework and become a patient. The organization proposes society’s understanding of lung cancer be medicalized by suggesting that society should properly consider the individual with the disease as a patient. However, the medical framework maintains a relationship between disease, identity-making and responsibility. How is the perspective of the problem of (unjust and stigmatizing) public attitude toward lung cancer patients shifted by medicalizing the relationship between identity-making, disease, and responsibility? In other words, how does shifting toward the medical frame diminish the moral aspect of disease-related identity? As LCA’s solution for the negative public attitude about lung cancer patients, the implication is that the moral aspect of the stigma framework would be diminished. This solution provides insight into LCA’s picture of what destigmatization looks like.

The relationship between disease, identity, and responsibility is maintained in the medical frame. The authoritative source of knowledge in the medical frame is more obvious and discrete in this frame. Additionally, the norms tend to be stated more
explicitly. Physicians create expectations for the patient. The norm is that he follow those expectations with a fair amount of accuracy. For the individual to call himself ‘patient,’ he must comply with medical recommendations and follow through with all medical treatments. Illich states that the medical frame is not objective, as LCA implies, rather “medicine is a moral enterprise and inevitably gives content to good and evil. In every society, medicine, like law and religion, defines what is normal, proper, or desirable.”

Medicine provides for an empirical basis for identity-making via diagnosis. However, identity from a medical perspective is based on diagnosis only in part; a patient identity is also based on an underrepresented component of role fulfillment that is considered reflective of the patient’s character.

By ascribing diagnosis, the medical field adds a new feature to the individual’s identity. As with the stigma framework, the medical frame poses a tightly intertwined relationship between identity and responsibility. Unlike the stigma framework, the basis for comparisons lie within medical rather than social knowledge. In the medical frame, the individual is initially considered a patient upon the first visit to the physician, if for no other reason than by virtue of physically being in the clinic. He is initially considered a normal patient, where the normal patient category is independent from the disease category. By this I mean, all individuals in the medical frame are subject to normalizing expectations from the physician, regardless of the disease. The normal patient, who complies with recommended medical treatment, is a category that cuts across all disease categories. Normal behavior in the medical space is constituted by the patient taking an active role in managing his disease. Medicalization emphasizes the individual’s role as a

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patient, which indicates that it is his responsibility to carry out reasonable medical recommendations that will stabilize or improve his condition. The ethical role is with the physician; however, medical care is ultimately the patient’s responsibility. Fulfillment of the patient role is the norm based on the medical establishment’s expectations. Ivan Illich characterizes the physician as “‘a moral entrepreneur, charged with inquisitorial powers to discover certain wrongs to be righted. Medicine, like all crusades, creates a new group of outsiders each time it makes a new diagnosis stick. Morality is as implicit in sickness as it is in crime or in sin.” This is distinct from the normal (social) individual, whose normal behavior is determined based on values determining expected social interaction. In both cases, definition of the norm conversely defines deviance. Those that deviate from the norm simultaneously exist as a type of person that would not naturally accept certain (biomedical) treatments, and as a category exists of patients whose behavior does not fit with other patient’s “normal” behavior. Deviance from medical expectation in this way are judged to be “non-compliant” patients. Judgment of the patient’s willingness to accept medical advice signifies an individual of poor character in that he is not an individual who prioritizes his health. This “bad” patient is different from the other “good” patients who value their health and enact the medical advice for which they paid. Those individuals whose behavior places them in the normal category are awarded the name ‘patient’ based on their merit. This kind of identity matches current behavior with the patient’s current character. Whereas identity in the stigma frame attempts to match past behavior with his current character. Therefore, lung cancer patients become responsible for managing their disease in order to manage and support their moral identity.

129 Ibid., 46
In some ways, the medical frame is a more accurate representation of the individual’s *current* moral identity. It does not represent the individual’s *overall* identity though. The argument that was raised in arguments against stigma still applies here: the disease identity (and resulting patient identity) again takes over the individual’s full identity. The medical framework does not avoid categorizing the individual on the basis of a single attribute. In this case the attribute may be the patient’s ability to conform to medical recommendations, but it is still the same identity-making problem as experienced in the stigma framework. An unstated expectation is still held by the physicians, who hold the authoritative role within the medical frame. The expectation that the patient will make his disease as agreeable to the physician as possible, meaning he will ensure it is managed, and adhere to the medical code. Deviance from expectation and judgments regarding the patient’s behavior still occur. Responsibility is still held by the patient.

The lung cancer patient signifies an agreement from the medical community that “lung cancer patient” is a legitimate category in need of care and, an agreement in the research community that this disease and the harm it represents to society is worth investigation. Endorsement by the medical community helps build the case for increased federal research funding. Medicalization of a disease perhaps increases the possibility that the patient will be able to access proper clinical care and enjoy higher awareness of the disease. However, this at a personal cost to the patient, who must first demonstrate the legitimacy of his identity. In the medical frame, the patient is expected to take on the good patient role. This is based on the assumption the patient appropriately accepts and understands the diagnosis and is compliant with the treatment plan. What this assumption really means is that society's expectation of the patient is that he accept the
medicalization of part of his self-concept, his identity. Furthermore, it becomes his responsibility to do so.

Difference shapes the way an individual is categorized, as well as the very category in which he is placed. The medical frame can be viewed as a way to operationalize difference; it becomes a tool for exclusion or inclusion. Difference carries the same function in the stigma framework, but based on different reasoning. The degree of difference would not be eliminated; as one enters the medical framework: he is categorized according to disease. He would occupy a space of generalized responsible patients or cancer patients, rather than of the group of irresponsible people who risked his health to smoke and are now paying the price. Realistically, that valence may continue to exist. However, medicalization offers a new way to determine the category the individual fits into. The medical frame matches the difference that exists: a medical pathology and diagnosis. Furthermore, it is a widely accepted and pre-existing category. LCA is able to offer the medical frame as a legitimate replacement for the stigma frame because society has already undergone several waves of medicalization, each time allowing medicine into their lives and self-concept, or identity. The work has already been done to create medical categories and discover medical pathology. The existence of the category and the existence of the disease separate people into their corresponding boxes apparently based on a diagnosis. However, moral identity is still applied to the individual based on his demonstrated commitment to prioritizing health(care). By becoming the responsible, compliant patient, he is able to take advantage of the health care treatments offered to him, assuming he has the means to do so.
Lung Cancer Alliance’s push to shift away from the stigma framework toward the medical framework has a serious pitfall. Given the newest campaign that promotes prevention by utilizing the newly approved low-dose CT screening, the individual at risk for lung cancer or diagnosed patient becomes a consumer of medical technology. Making use of interventions such as low-dose CT ostensibly seems to be an expression of the patient’s rights to equal care and decrease the marginalized status of lung cancer via early detection. However, the patient must consume medical care in order to enjoy any benefits to his health status. He may not have the financial means, transportation, or time to do so. However, such externalities must be overcome to maintain “good patient” status and, therefore, a positive moral identity. This disproportionately favors some patients over others, and the overall lung cancer patient group remains marginalized. Though, medicalizing lung cancer may offer some benefit to the patient in the form of giving him more control over his identity, should he appropriately carry out the patient role, the troubled relationship between identity-making, responsibility and disease finds no relief in the medical frame.

The stigma and medical frameworks for disease are treated by Lung Cancer Alliance as shorthand for the types of relationships they signify. The traditional medicalization literature also collapses the significance of medicalization by deferring to arguments about medical authority and jurisdiction. While the theoretical literature does not support the simple equation medicalization = destigmatization, this equation is how LCA envisions destigmatization. The simple statement precludes further inquiry and defers to a statement about the correctness of LCA’s picture. Additionally, the very definition of medicalization encodes a critique of the phenomenon by characterizing it as
an *inappropriate* application of medicine to a social problems. Yet, for the discussion at hand, it is important to set aside judgment about the phenomenon in order to give adequate attention to the picture of destigmatization LCA holds. If we begin from a neutral stance about applying the medical framework, and from a place where medical authority is given, the detailed relationships the medical frame encodes can be examined. The relationship between disease, identity-making and responsibility is applicable to the medical frame, but through a more complicated interaction than found in the stigma frame. LCA implies these relationships and refers to them in the campaign in a way that the audience immediately understands. In this way the relationships and contributing features, such as comparison, difference assessment, and normative judgment, are collapsed. Because the audience understands, LCA is able to used stigma and medicine as a framing device without theorizing the concepts. Upon exploration, the shift toward the medical frame connects relationships between disease, identity-making, and responsibility in a different way than they were connected in the stigma framework. In the medical framework, the individual is given the patient label before a comparison and assessment of difference occur. The patient must demonstrate that he is taking active responsibility for his disease in the manner prescribed by the physician. If the individual follows the expectations, no difference is found between his actions and the norm. Therefore, he is allowed to continue as a ‘normal patient.’ If he does not fulfill his patient role as expected, he deviates from expectation. By no longer fitting with the norm, compliance with medical recommendation, the patient is considered non-compliant and considered a ‘bad patient.’ In other words, the patient must work to maintain his identity.
He must demonstrate responsibility in order to sustain the current ‘good patient’ identity.

Reflection of this sort on the individual’s identity maintains the moral aspect of disease.
CHAPTER 6

CONCLUSION

Difference can be assessed from multiple perspectives. Perceived difference has a strong impact on identity-making. Within the stigma framework, difference is assessed based on comparison between the observed and the expected. Expected behavior is based on an embedded norm that often goes unacknowledged. The invisible cultural norm leads to a moral explanation for the resulting disparity. In this way understanding of identity adopts a positive or negative quality. These are major features of identity-making that are made visible when framing a disease in terms of stigma.

The definition of stigma has morphed over the past 50 years to emphasize the negative connotations of the concept that take precedence in the common-sense understanding of stigma. This way of understanding disease with a set of assumptions and responded to with a set of generally accepted practices, or this framework, is therefore infused with this negativity. Whether or not this diminishes the integrity of the definition, it is indicative of how the concept is commonly applied. Disease is a common area where this kind of identity-making is applied. Several authors cited in this thesis, including Goffman and Sontag, make the case that disease is historically believed to reveal the underlying character of the diseased. Thus, these actions can simultaneously be considered as identity-making for the individual, and disease-identity-making for the group. Lung cancer provides an ideal space to examine the relationship between disease and identity. The individual with lung cancer assumes a lower status than other types of

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individuals with cancer due to the perception that he knowingly risked his own health. The common sense knowledge says “he did it to himself.” Therefore, unlike others with cancer, he does not deserve sympathy when it comes time to bear the consequences of his misbehavior. This reasoning is extrapolated to the group level when this kind of disease identity is used as a method to determine the claims individuals can make on society.

LCA’s campaign asserts that public attitude about lung cancer is stigmatizing. Lung cancer should not be stigmatized, according to LCA. The non-profit organization’s argument is that the disease is inappropriately understood within the stigma framework. Within this frame, lung cancer patients are primarily understood as moral actors. Because of this, individuals with lung cancer are denied opportunities that have shown to greatly benefit other cancer patients. Therefore, individuals with lung cancer should be understood as patients only. By shifting this understanding of the diseased, society will be fulfilling its responsibility to allow the patient a structure within which to make claims on society. Lung Cancer Alliance, the only organization of its type to target the stigma framework, implies that understanding of the disease should be medicalized. Identity-making and responsibility are features of stigma that are operationalized in the text and visuals included in the “No One Deserves to Die” campaign released by Lung Cancer Alliance in June 2012. The case highlights that membership to a devalued disease group not only impacts the individual on a personal level, but also impacts how society approaches the disease. In this way, social responsibility has a direct impact on the tangible markers of injustice against individuals with lung cancer. By striving to change public attitudes about lung cancer, LCA aims for a morally neutral frame for this disease.

This theoretical research provides a review of the social interactions that serve as
a basis for creating the cultural understanding disease. Both the medical and stigma frameworks influence the relationships between disease, identity, and responsibility. It is significant that Lung Cancer Alliance tells the audience that the injustices felt by lung cancer patients is “stigma.” The framework of stigma is considered a moral understanding of disease by LCA. However, as LCA implies, this is a moral understanding that has gone unexamined. The organization tells the narrative of lung cancer and negative social attitudes as a flat map of linear thinking: stigma= unjust attitude = exclusion. Society has a common sense understanding of lung cancer that glosses over the actual social interactions that generate the relationship between disease, identity, and responsibility. Complex social interactions come to light by asking how this relationship is made, given that Lung Cancer Alliance’s stigma narrative compresses the complexity of the story. By calling the phenomenon ‘stigma,’ LCA is able to package a whole process of social interaction into one term that is assumed to be understood by the audience. When breaking this package into its pieces, we see that identity is attributed to the individual with lung cancer when society compares him with other types of cancer patients. When difference is seen between these types of patients, the difference is explained by society with the insertion of a normative judgment. The difference attributed is often based on unstated norms, according to Martha Minow. The normative judgment alters the individual’s identity. This process of identity-making leads to corollary responsibilities for society and for the individual. The stigmatized individual is expected to take responsibility for his past actions, according to Goffman. Yet, LCA states larger society is responsible for stigmatizing individuals with lung cancer. It is society’s social attitudes based in moral judgments of lung cancer that are responsible for
preventing progress in lung cancer research and improvements to mortality rates. The stigmatized are told that the social responses they encounter when managing their disease are unacceptable. The stigma attached to their disease is no fault of their own; rather, it is due to an unexamined social attitude. This attitude causes the proxy effects of stigma in the form of underrepresentation in federal research funding, minimal intervention to improve 5-year-survival rates, and low awareness of the disease.

Lung Cancer Alliance offers medicalization of public attitude toward lung cancer as a solution for the injustices felt by lung cancer patients in terms of federal research funding, clinical care, and awareness. In the medical framework, identity is earned by successfully assuming the patient role. Where identity in the stigma framework retroactively interacts with responsibility by assuming that the individual is responsible for causing the disease, identity from the medical perspective is determined by active responsibility for managing the disease. Fulfillment of the patient role is the established norm based on the medical community’s expectations. Responsibility for the disease is shifted back to the patient. This, perhaps unexpectedly, has a moral implication. Though it de-emphasizes a patient’s past transgressions against his health, the medical framework only allows a patient a positive identity when he properly carries out the patient role. However, the medical frame provides a method for the individual to take active responsibility for his disease. By fulfilling the patient role, the individual can legitimately claim his rights to representation. Therefore, medicalizing the relationship between identity-making, disease, and responsibility does not remove moral implications about the individual’s character. Nor does understanding the disease in the medical framework absolve the patient of personal responsibility of his disease. Rather, it offers a different
organization and interaction of the relationship between disease, identity, and responsibility.

This research effort has opened more questions than it has answered, as most do. In-depth inquiry into the genealogy of the concept/framework of stigma would provide a more complete picture of the way this particular frame for understanding disease has evolved. In addition, further research into what kind of disease frame would reduce harms felt by patients would have a broad impact. Many other types of disease whose cause is blamed on the diseased, such as mental illness, HIV/AIDS, obesity, alcoholism, and disability, experience some level of stigma with tangible harms unique to each situation. This research shows that the relationship between the disease, identity-making activities and responsibility is not altered significantly by shifting the framing of the disease from stigma toward medicine. Though this research does not aim to analyze the effectiveness of the campaign or its recommendations, it may be that Lung Cancer Alliance’s solution to the problem of injustice may not be the most prudent. Finally, the question of how the disease character, especially its mortality-rate ranking, alters understanding of the disease identity is especially interesting. One may ask if, and how, the stigma frame changes in relation to the social implications of the disease. This question could be broadened to ask, how a different social context changes common understanding of and assumptions about a particular disease. Lung cancer is not just an American problem. Allen Brandt describes the growing problem of smoking and lung cancer as exported to developing countries by American companies disfavored domestically. This inquiry has unpacked the step-wise behaviors that build the stigma framework; awareness of the features of these frames that produce harms for the
individuals/patients provides “another terrain for reconsidering the relationships and patterns of power that influence the negative consequences of difference.”¹³¹ Future attempts to alter these relationships could build on this knowledge to bring about a true shift away from understanding disease in stigmatizing terms. Even simple awareness of how a stigma framework causes harms may benefit future lung cancer patients in this and other countries. Such awareness may provide them with equitable treatment before the American framework of stigma is exported and causes deadly marginalization. Such inquiries would be able to build off and contrast against knowledge provided here about the identity of lung cancer, the second largest killer in America.

¹³¹ Ibid., 78
REFERENCES


http://www.myphilanthropedia.org/how_we_rank.


APPENDIX A

“NO ONE DESERVES TO DIE” PHASE I CAMPAIGN POSTERS
“No One Deserves To Die” Campaign posters were displayed on bus bench shelters, buildings, payphones, print media, and on the internet. They were released exactly as shown below with no explanation of the meaning behind the statement or the campaign for one week in June 2012.

Lung Cancer Alliance June 2012

132 All images found in Appendix A and B can be found on the advertising agency, Laughlin Constable, website. Laughlin Constable. 2012. “Lung Cancer Alliance: No One Deserves to Die” http://www.laughlin.com/clients/lung-cancer-alliance/campaigns/no-one-deserves-to-die/work/hipsters-deserve-to-die

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THE SMUG DESERVE TO DIE
CRAZY
OLD AUNTS
DESERVE
to die
HIPSTERS DESERVE TO DIE
THE GENETICALLY PRIVILEGED DESERVE TO DIE
THE TATTOOED DESERVE TO DIE
APPENDIX B

“NO ONE DESERVES TO DIE” PHASE II CAMPAIGN IMAGES
Images released after the initial week of the campaign. At that time, the campaign and its meaning were explained to the public audience.
NO ONE DESERVES TO DIE

NO ONE DESERVES TO DIE
NO ONE DESERVES TO DIE

NO ONE DESERVES TO DIE
Hipsters Deserve To Die –
the extended version with an explanation of the campaign and the problem it is meant to address.
The text reads:

HIPSTERS DESERVE TO DIE if they have lung cancer. Many people believe that if you have lung cancer you did something to deserve it. It sounds absurd, but it’s true. Lung cancer doesn’t discriminate and neither should you. Help put an end to the stigma and the disease at NoOneDeservesToDie.org.

Lung Cancer Alliance
APPENDIX C

INTERVIEW WITH GABRIELE GEIER, COMMUNICATIONS MANAGER AT LUNG CANCER ALLIANCE
Prepared Questions

1. How did you measure success of the campaign?
   a. Increased public discourse about lung cancer?
   b. Impact on legislative action?
   c. Influx of research funding?

2. What is Lung Cancer Alliance’s definition of stigma?

3. Was the campaign release targeted to certain areas?
   a. How did you choose those areas?
   b. Is Lung Cancer Alliance’s new campaign promoting risk awareness focused toward the same audience?

4. Will reducing injustice and stigma associated with the disease break the link between lung cancer and smoking?

5. Has Lung Cancer Alliance thought about the negative effects of reducing stigma, i.e. opening the door to increased incidence of smoking?

6. What is next for Lung Cancer Alliance?

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